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## **University of Alberta**

Learning Disability Assessment: The Parents' Perspective

Michele Pentyliuk C



A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Master of Education

in

Special Education

Department of Educational Psychology

Edmonton, Alberta

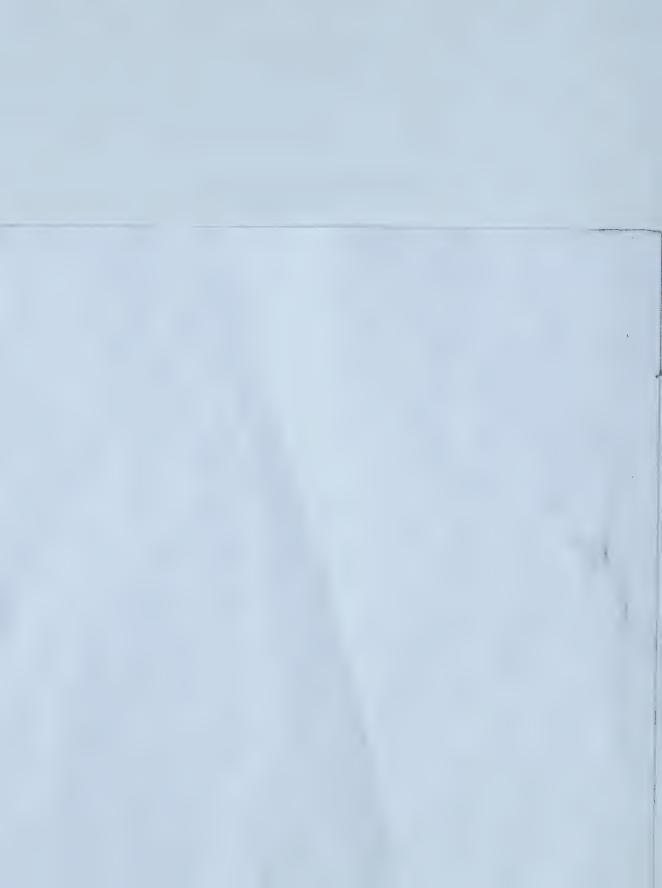
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### University of Alberta

Faculty of Graduate Studies and Research

The undersigned certify that they have read, and recommended to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled "Learning Disability Assessment:

The Parents' Perspective" submitted by Michele Pentyliuk in partial fulfillment of the requirements for the degree of Master of Education in Special Education.



Dedication

To Alexandra, Zachary, Natasha and Steve who make all that I do worthwhile.



#### Abstract

The purpose of this research was to explore parents' experiences, concerns, and feelings surrounding the psychoeducational assessment and diagnosis of their child with a learning disability by a school psychologist or consultant. Two interviews were conducted with 6 sets of parents whose children had been diagnosed with learning disabilities within 6 months of the initial interview. Parents were asked to describe in detail their feelings, experiences, and concerns before, during, and following the assessment. Data was analyzed using a qualitative framework. Parents in this study viewed the assessment as a means of gaining information that would help them understand their children better, but described only minimal involvement in and understanding of the assessment process. Despite confusion over the results and diagnoses, parents utilized the information they gained to enhance their coping skills, and to continue their pursuit of support services to meet the needs of their children with learning disabilities.



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### Chapter 1

#### Introduction

When a child with suspected learning disabilities is referred for special help, the first step is often the completion of a psychoeducational assessment by a school psychologist or consultant in order to make a differential diagnosis. The focus of the assessment is often on the child as the source of the disability, and interventions are implemented within the context of the educational system (Kysela, McDonald, & Brenton-Haden, 1992). If one subscribes to the family systems theory that family members interact in a transactional manner (Minuchin, 1985), then this approach to assessment and intervention is incomplete. The practitioner who conducts an assessment without parental involvement fails to take into consideration the many aspects of the child's environment that may be contributing to the learning difficulties, as well as the strengths parents and families possess.

Although there is a great deal of literature in the area of psychoeducational assessment and learning disabilities, little research is available that addresses the nature of the experiences of parents when assessments are conducted within the school setting. The choice of a qualitative approach for this study was determined by the aim of the inquiry: to formulate thick descriptions of parents' experiences. The results of this study may be a precursor to more qualitative or quantitative research into parental involvement in the assessment process.

### **Purpose**

The purpose of this research is to explore parents' experiences, concerns, and feelings surrounding the psychoeducational assessment and diagnosis of their child with a



learning disability by a school psychologist or consultant. More specifically, this qualitative research strives to better understand:

- 1. What are parental concerns, feelings, and expectations prior to the assessment?
- 2. What are parental perceptions of their role in the assessment?
- 3. What are parental experiences of the feedback session?
- 4. How does the assessment process and subsequent diagnosis affect family adaptation? Specifically, how does the assessment and diagnosis enhance parental understanding of their child's learning disability, promote the development of support systems, and enhance coping strategies?

### Definitions

For the purpose of the study, the following definitions will apply:

Parent(s): Single parents or couples who have been legal guardians and primary caregivers of a child for at least 5 years.

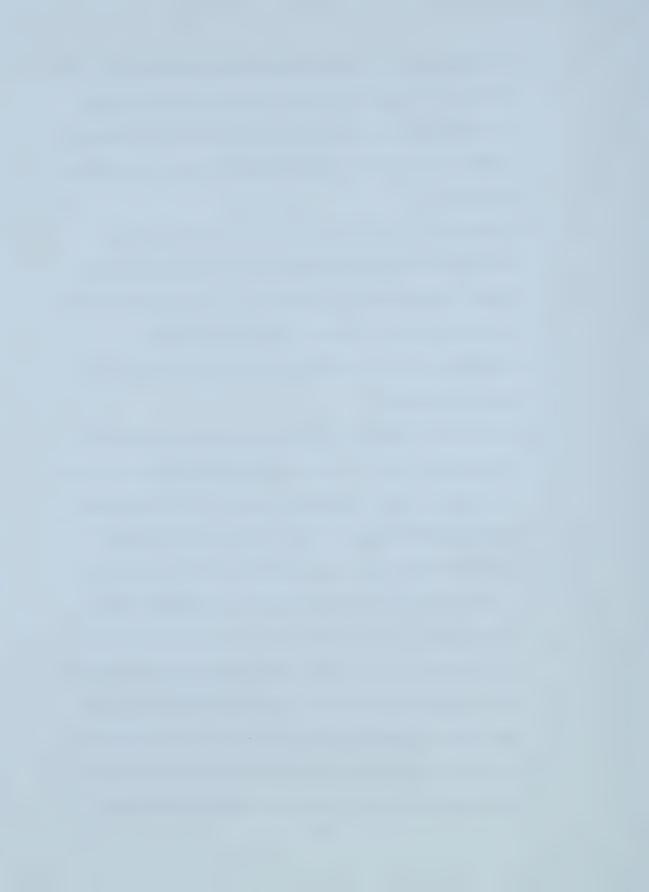
Psychoeducational Assessment: The administration, by a school psychologist or consultant, of cognitive tests (e.g., Weschler Intelligence Scale for Children-Third Edition [WISC-III] or Stanford Binet Intelligence Scale- Forth Edition [SB-IV]), as well as a battery of standardized achievement tests and informal assessment tools.

Learning Disability: A disability characterized by average performance on a cognitive assessment, and significant delay in one or more areas of academic achievement. For the purpose of this study, the definition provided by Alberta Education was utilized. They adapted this definition from the Learning Disabilities Association of Canada (LDAC):



- underachievement as indicated by uneven patterns of development; e.g., well-developed oral language skills vs. poor written language skills, and/or by discrepancies between potential and academic achievement; e.g., average performance on a test of intelligence but significant delays in reading and/or mathematics.
- central nervous system dysfunction indicating that the source of the
  difficulties is found within the person and is not a consequence of outside
  factors. According to the LDAC definition: "...due to identifiable or inferred
  central nervous system dysfunction...intrinsic to the individual...".
- difficulties with one or more of the basic psychological processes, such as attention, memory, etc.
- specified areas of difficulty in which learning disabilities are often noticed.
   Common areas included are spoken language, academic and conceptual. Less frequently included are difficulties involving social skills, self-regulation, spatial orientation, integration or motor abilities. The LDAC definition specifies that the disorders are manifested in any of the following areas:

   "... attention, memory, reasoning, coordination, communication, reading,
   writing, spelling, calculation, social competence and emotional maturation."
- an exclusionary clause which reinforces that learning disabilities are different
  from other handicapping conditions and do not arise from them nor do they
  arise from environmental influences. Even though a learning disability may
  co-exist with other handicapping conditions (sensory impairment, cognitive
  delay, social and emotional disabilities), and environmental influences



(cultural differences), it is not the result of those conditions or influences.

(Alberta Education, 1996, p. 2)

#### Justification

Research into parental experiences of the assessment process emerged through my professional experience as an educational consultant conducting assessments with both children and adults with learning difficulties. I began this work in 1987, following a 2 year stint as a special education teacher, after which I joined a group of psychologists in a private practice. Most often, I completed psychoeducational assessments with children whose parents had concerns regarding their children's learning ability or achievement. Parents requested assessments in order to provide them with more information so that they could better support their children, and also to help establish what support and/or strategies may need to be implemented at the school.

Parents expressed a variety of reasons for seeking an assessment at a private clinic as opposed to utilizing the resources available through the school system. One frequently stated reason for this choice was the long wait that would occur due to the high demand on the services provided by school psychologists and reading specialists. Parents also stated that their children were not considered eligible for assessments because they were not doing "badly enough." In addition, some parents indicated that they chose a private assessment because they wanted to be in control of the dissemination of the assessment information. It was apparent that parents sought assessment through a private agency out of either necessity or desire.

Within the clinical context in which I worked, parents were viewed not only as the primary source of information about their child's developmental history, medical status,



educational history, and personality, but also as the people who had the most influence on their child's life. Through my experience as a clinician as well as my studies in areas including family systems theory and early intervention practices, it became more and more clear to me that my role was not only to provide accurate diagnostic information, but to support parents in their search for understanding of their child's learning difficulty. and to help parents utilize their resources to continue to adapt to having a child with unique learning needs. However, I began to wonder how well I was accomplishing this goal, and questioned to what extent the assessment was able to enhance family adaptation. It was these questions that lead me to the broader question of parental experiences of the assessment process within the school setting. Because it was my experience that most children who undergo an assessment do so within the school setting. I felt that it was important to discover their perceptions of the level and kind of involvement they had, and in what ways the information they received may have fostered family adaptation.

My professional experience in the area of psychoeducational assessment in a familyfocused practice creates several biases that may have influenced my data gathering as
well as my interpretation of the data. Although attempts were made to suspend my biases,
the questions I asked, the way in which I analyzed and interpreted the data, and the
conclusions that I made, all were colored by my previous experiences and the way in
which I view families and assessment. Despite this, it is my hope that the voices of the
parents who were interviewed for this research speak for themselves, so that
professionals gain insight into parental perspectives of the assessment process.



#### Chapter 2

#### Literature Review

Rationale for research into parental perspectives of assessment is supported within a historical context. There is a great deal of research and literature spanning several decades in the area of learning disabilities. This literature most often addresses topics related to the process of and issues surrounding assessment and diagnosis, academic performance, teaching strategies, and other school related themes. There is less literature that examines parents or families of children with learning disabilities, although there is research that addresses various issues affecting families of a child including family systems theory, the differences between families with and without a child with a learning disability, as well as various aspects of family functioning and adaptation. Although there has been some research into the affect assessment has on parents and families of children with disabilities (e.g., parents of children with sensory impairments, mental and physical handicaps), I was unable to locate research addressing the experiences of parents in situations where the diagnosis of their child with a learning disability was made within the school setting. The following literature review provides a synthesis of some of the related research in order to provide a solid background and justification for this study into parental experiences of psychoeducational assessment.

## Learning Disabilities: Definitions and Assessment Issues

Although the term learning disability has existed since the 1960s (Gearhear, 1973), there has been considerable debate as to what constitutes a learning disability, how learning disabilities are best diagnosed, and what the relationship is between testing for identification purposes and testing for educational programming (Scruggs & Mastropieri,



1995). Siegel (1999) stated, "If one examines all the books and articles that have been written about learning disabilities, the state of the field seems chaotic" (p. 305). Therefore, no thorough discussion of the assessment of learning disabilities would be complete without some mention of the debate surrounding the definition of the term, and the process of identification. These two concepts are enmeshed as the former depends on the latter. A clear definition of a disability allows for the development of appropriate assessment practices. Therefore, the ambiguity in the definition of a learning disability opens up the debate as to what constitutes an accurate and appropriate assessment.

Prior to the term "learning disability" the term "Minimal Brain Dysfunction" (MBD) was used to describe individuals with near average or higher intelligence who had not sustained any brain damage, but had learning problems similar to those who had. The term learning disability replaced MBD, due to the shift away from the medical focus toward an educational focus (Smith, 1998). Most current studies published in psychological, educational, and neuropsychological journals define people with learning disabilities as individuals with at least average ability to process and retrieve some information from their environment who unexpectedly have difficulty performing at their age level on specific cognitive or academic tasks. These individuals exhibit performance on general intelligence tests comparable to children their own age, but they have problems on academic tasks. The extent of their academic difficulties ranges from mild to severe.

Although most authors and researchers agree that a learning disability involves some sort of discrepancy between cognitive ability and achievement, other characteristics of



this disability are not universally agreed upon. One widely accepted definition of learning disabilities is:

A general term that refers to a heterogeneous group of disorders manifested by significant difficulties in the acquisition and use of listening, speaking, reading, writing, reasoning, or mathematical abilities. These disorders are intrinsic to the individual, presumed to be due to central nervous system dysfunction, and may occur across the lifespan. Problems in self-regulatory behaviors, social perception, and social interaction may exist with learning disabilities but do not themselves constitute a learning disability. Although disabilities may occur concomitantly with other handicapping conditions (for example sensory impairment, mental retardation, serious emotional disturbance) or with extrinsic influences (such as cultural differences, insufficient or inappropriate instruction), they are not the result of those conditions. (Hammill, 1990, p. 77)

When one compares this definition to accepted beliefs of what a learning disability is, both ambiguity and contradictions are exposed. Although it is generally accepted that a learning disability is different than other learning disorders such as mental handicaps, the definition presented by Hammill suggests that learning disabilities can occur with mental handicaps. As stated previously, this confusion over what does or does not constitute a learning disability opens up the field to a great deal of debate, and further complicates the process of assessment.

The discrepancy definition where a learning disability is defined as a difference between achievement and potential has persisted for more than 30 years despite significant controversy regarding its relevancy and utility. However, no universal specific



guidelines have been established to measure the exact magnitude of the discrepancy, and no instructions have delineated how to measure or demonstrate its existence (Finlan, 1992). Stanovich (1999) argued that "the term learning disability is redundant and semantically confusing" (p. 350). He added that the umbrella term only causes confusion and suggests that each domain specific disability should be treated separately. Fletcher, Francis, Rourke, Shaywitz, and Shaywitz (1992) stated that:

Identifying children as learning disabled based on a comparison of test scores involves a host of complex statistical issues.... This complexity is magnified when the exclusionary criteria are added, such that only certain types of discrepancies can be represented as learning disabilities. (p. 555)

Discrepancy-based approaches are utilized in the assessment of learning disabilities in an attempt to operationally define the concept of an ability-achievement gap. The implicit assumption for including discrepancy scores in the classification of learning disabilities is that children who have reading, writing, or math difficulties, not accompanied by low IQ, are distinct in cognitive processing from learners with slow or mildly retarded rates of learning. "To date, discrepancy scores have become the *sine qua non* of defining children as having learning disabilities" (Fletcher et al. , 1992, p. 555).

Discrepancy-based methods of classification employ a mathematical formula to the results of standardized measures of intelligence and achievement. There are several ways to establish discrepancy including the years below model, the expectancy model, the standard score differences model, the reliability model, and the standard regression analysis. Proponents of discrepancy based approaches focus on issues related to the technical adequacy of measurement instruments and the magnitude of discrepancy for



statistical significance. They acknowledge the statistical shortcomings of their varied approaches, however, they believe that discrepancy formulas are an important component of the assessment process (e.g., Evans, 1994; Finlan, 1992; Schuerholz et al., 1995).

Proponents of alternative approaches to the identification of children with learning disabilities focus on the measurement of variables that represent component skills requisite for academic success, and believe that discrepancy-based formulas are a leading cause of over-identification and misidentification of school-aged children with learning disabilities. They propose the use of methods that more accurately assess what a child with potential learning disabilities knows and how well he or she responds to intervention (e.g., Swanson, 1996). One major criticism of discrepancy formulas has been the model's inability to accurately distinguish learning disabled children from other groups of children who are having difficulty in school (i.e., language and ethnic minority students).

For students from economically depressed urban areas, for students whose acculturation is different from that of the standardization population of the assessment instruments used, for students whose native language is not English, and for those students who have suffered lack of opportunity to learn, the diagnosis of specific learning disabilities should be an extremely complex process. Ironically, it often appears that these very students are the ones most frequently classified as learning disabled. (McNamara, 1998, p. 10)

Proponents of alternate measurements argue that practitioners utilizing discrepancy-based methods focus their discussion on computation (e.g., establishing formulas that control for regression and overidentification), and not necessarily on issues of construct validity (meaningful classification systems). Therefore, the refinement of methodology



in school identification of children with learning disabilities has operated independent of construct validity issues (similar to an argument that a test may be reliable but not necessarily valid). The most serious of these conceptual challenges to the field is that cognitive profiles of children with learning disabilities cannot always be discriminated reliably from generally low achieving children when using traditional assessment measures (Siegel, 1992, 1999). Swanson (1996) argued that discrepancy and nondiscrepancy-defined groups of poor achievers are more alike than different. "It is also true that we do not know why a discrepancy exists between IQ and achievement. We have not consistently found cognitive processes that could account for the discrepancy" (p. 4). Humphries and Bone (1993), in their study comparing children with learning disabilities and slow learners, found no clinically significant differences in academic achievement.

There are additional arguments in the literature that dispute the use of discrepancy formulas for the diagnosis of learning disabilities. One argument is that there is no evidence to substantiate the claim that IQ tests capture the construct of potential (Swanson, 1996). Further, the administration of standardized tests used to calculate discrepancy scores have been criticized for their limited ability to translate into practical programming interventions (Shruggs & Mastropieri, 1995). Alternative assessment practices such as Curriculum-Based Measurements (CBM), Dynamic Assessment (DA), and Performance or Portfolio assessment have been developed in an attempt to link diagnosis, remediation, and contextual relevance.

Nondiscrepancy approaches typically view potential in a very different manner than those in favor of discrepancy models. Rather than defining potential as the score



resulting from a series of questions and activities on standardized tests, potential is viewed as what a child can do under optimum conditions. Therefore, minority group children and other groups who are often at a disadvantage when undergoing standard intelligence testing, are not at a disadvantage using these alternative methods. This reduces overidentification. In DA, potential is measured in terms of the distance between, and/or changes from unassisted performance to a performance level with assistance (Scruggs & Mastropieri, 1995). Fuchs and Fuchs (1998) believed that a "treatment validity" approach is the most appropriate approach to the identification of and programming for learning disabilities in children. It requires that special education be considered only when a child's performance reveals a dual discrepancy: The student not only performs below the level demonstrated by classroom peers, but also demonstrates a learning rate substantially below that of classmates. "CBM deliberately integrates key concepts from traditional measurement theory and from the conventions of classroombased observational methodology to forge an innovative approach to assessment" (Scruggs & Mastropieri, p. 208).

Another reported value of nondiscrepancy approaches is that they provide a great wealth of information regarding what a child can do. CBM involves administering a series of equivalent assessments at regular intervals throughout the year. In this way the teacher can evaluate progress throughout the year on content specific information.

Portfolios require the collection of actual work samples that can be compared as the child progresses (Rueda & Garcia, 1997). When teachers have access to content specific assessment information, they can not only evaluate progress over time, but can use diagnostic problem solving to determine how to improve instructional programming.



Assessment information gathered through approaches like CBM, DA, and portfolios yields information about standing as well as change, about global competence as well as skill-by-skill mastery. Therefore, it can answer questions about individual differences, about intraindividual improvement, and questions about how to strengthen individual student's programs. Fuchs and Fuchs (1998) claimed that these approaches focus "systematic and intensive effort at maximizing regular education's potential for individual students and reserves judgement about the need for special education until the effects of individual adaptation within the classroom environment have been explored" (p.216).

In order to overcome many of the shortcomings of standardized assessment and discrepancy-based diagnostic approaches, several nondiscrepancy-based approaches have been developed. The difficulty with these alternative approaches is that although they are more authentic and provide more specific and detailed information to facilitate instructional planning, they are not well grounded in psychometric properties, (i.e., they are highly clinical and have poor validity), and are often time-consuming propositions that add additional burdens to already over-burdened teachers. Continued research into these alternative assessment approaches may lead to their greater acceptance and utilization (Shruggs & Mastropieri, 1995).

Because of the diversity among students with learning disabilities, the vagueness of the term, and the lack of consensus as to what constitutes a learning disability, researchers tend to study heterogeneous groups of students. As a result of the diverse nature of these groups, comparing and evaluating research in the area becomes a complex task. It is, therefore, essential that researchers describe as precisely as possible the methods and definitions used to classify students with learning disabilities. Smith (1998)



argued that when better descriptions of samples are provided, researchers are in a better position to generalize findings and replicate studies. A basic understanding of the complexity of the issue of learning disability definition and identification provides practitioners with the necessary background to understand research into this area, and provides researchers with the necessary information to select appropriate samples.

## Psychoeducational Assessment

While professionals in the field remain quite divided on issues surrounding the identification and assessment of learning disabilities, the classification of children based on discrepancy definitions and formulas continues in schools and clinics. The data gathered through the psychoeducational assessment is utilized to make decisions regarding student placement and intervention practices (Alberta Education, 1996). Strawser (1993) suggested that the process of assessing a child with a learning disability is the same as diagnosing any sort of learning difficulty or handicap. She stated that the "diagnosis of any disability is not an event, but rather a goal-oriented process that is guided by a series of questions at each stage" (Strawser, p. 87).

The view of the purpose of psychoeducational assessment has evolved over time. Salvia and Ysseldyke (1981) suggested that the purpose of psychoeducational assessment is to "provide students, parents, teachers, school psychologists, and other professionals with information to assist them in making decisions that will enhance students' educational development" (p. 14). Ten years later, Jackson (1991) offered a broader explanation of the purpose of psychoeducational assessment, suggesting that it is to provide insight into the child's way of perceiving the environment, and how he or she uses those perceptions to adapt, as well as developmental, neurological, and



circumstantial factors that affect the process of adaptation. These perceptions of the purpose of assessment suggests a shift away from investigating only the factors which are contributing to the child's difficulties, towards including an assessment of the competencies and resources within the family and the school that may be utilized to help the child.

More recently, McNamara (1998) stated that the critical question to be answered through an assessment is: "Is there sufficient information, from multiple forms of evidence, to conclude that perceived underachievement is the result of a pathological condition inherent to the student..." (p. 49). He proposed six principles that should be used to guide educational assessments:

- 1. There must be a clear definition of the purpose of the assessment;
- 2. Diagnostic questions must guide the assessment;
- 3. Multiple forms of evidence of student performance must be gathered;
- 4. Evidence of achievement must be gathered over time and in a variety of contexts;
- 5. Evidence of student performance must be based on curriculum materials and experiences that are familiar to the student; and
- 6. Evaluators must be able to accept lack of closure. (McNamara, pp. 46-47)

McNamara believed assessment is not a process that involves the administration of a standard battery of tests, but the careful selection of assessment tools to match the needs of the child and the diagnostic information required. For example, if a child is having difficulty learning to read and the teacher questions her ability to hear and sequence sounds, then not only should measures of her reading ability be administered, but other



tools that will evaluate her auditory processing and phonemic awareness. McNamara believed that the assessment should not be a one-time event, but should involve multiple measures of ability, and should include materials the child is familiar with, not just standardized measures. Finally, those conducting assessments need to accept that reasons for difficulties can not always be found, and that there may be a need for ongoing assessment.

Psychoeducational assessment includes the administration of a standardized test of intelligence (most typically the Weschler Intelligence Scale for Children-Third Edition) as well as other standardized and nonstandardized tests, parent/teacher observations, and interviews (NcNamara, 1998). Sattler (1990) described norm-referenced (standardized) tests, interviews, observations, and informal assessment as the "four pillars of assessment" (p. 3). In most instances, it is the school psychologist who administers these tests, and who must weigh the evidence gathered from various sources and determine whether a student is classified as learning disabled or some other handicapping condition (Davidow & Levinson, 1993).

The process of psychoeducational assessments varies depending on the setting (i.e., school or clinic) and the model utilized by the practitioner. Jackson (1991) specified that the process of assessment has four clearly defined stages: (1) referral, (2) testing, (3) feedback to parents, and (4) follow through of recommendations. A more comprehensive view of this process is described in Alberta Education's (1996) Teaching Students with Learning Disabilities manual. This manual describes a collaborative model of identification and program planning that involves four steps: Classroom Screening or Planning, Referral to Student Support Team, Follow-up Student Support Team Meetings,



and Individual Program Planning. In the pre-referral stage, parents or teachers gather pertinent information and explore intervention strategies. It involves communication between the teacher and the parents, and may result in finding a solution to the problem without further assessment. Unfortunately, this pre-referral stage is often given only cursory attention (Alberta Education, p. 56).

If the initial interventions do not prove to be effective, this model suggests that a referral be made to a student support team consisting of teachers, parents, the administrator, the students, and other professionals who may have relevant expertise. Only when this team feels that they do not have sufficient information is a student referred for more formal assessments. A follow-up meeting is held when further assessments have been completed in order to share information, and to plan program interventions. If an Individual Program Plan (IPP) is required, the team meets regularly to review and evaluate the effectiveness of programming and accommodations (Alberta Education, 1996). Although this model of assessment and intervention planning is comprehensive and outlines the necessity of parental involvement in all stages of the process, I found no information or research documenting the extent to which this model was being followed in schools. It is my experience that most school assessments follow Jackson's (1991) four-step process, and involves parents only at the feedback stage.

Davidow and Levinson (1993) suggested that although appropriate intervention depends upon accurate assessment and diagnosis, there is considerable evidence suggesting that diagnoses made by professionals are unreliable. In the field of learning disabilities, this is partly due to the vagueness of the term learning disability, as well as other factors including differences in theoretical orientation, and how psychologists



weigh the importance of the various diagnostic cues such as interview data, and IQ test results. As a result, diagnosis may vary from psychologist to psychologist even when diagnostic criteria are clear, and operational definitions are in place.

# Family Systems and Learning Disabilities

Although many models of assessment advocate the gathering of multiple sources of information, approaches to assessment and intervention by school professionals have been based most often on linear models where the child's difficulty is assumed to stem from a specific cause (e.g., Chittooran, D'Amato, Lassiter, & Dean, 1993; Daley & Nagle, 1996; Fletcher et al., 1992). Most definitions and criteria address the deficits within the child, and therefore, focus on the child as the source of the learning disability (e.g., Edmonton Public Schools, 1999). The assumption is that there are specific neurological deficits or differences that have resulted in learning difficulties in one or more academic areas. Other authors view learning disabilities in a much more holistic manner (e.g., Green, 1989; Kysela et al., 1992; Perosa & Perosa, 1982). Rather than seeing the child as the source of the disability, a learning disability is seen as a product of the child's unique cognitive patterns and characteristics, as well as family and educational environments. The focus is broadened to include not only the child, but also the family and school, and the interactions between them. The assumption in this approach is that the same origin may lead to different outcomes depending on the systems of which the children are a part.

The model that comes closest to incorporating a contextual, interactional view is a systems model (e.g., Minuchin, 1985). This model grew out of the dissatisfaction with the traditional reductionist-mechanistic approaches that dominated nineteenth- and



twentieth-century scientific thinking. This mechanical approach attempted to explain events by the development of a linear series of cause and effect equations. The assumption underlying this theory was the belief that every event had an ultimate causality. Systems theory, first introduced by Ludwig von Bertalanffy in 1928, provided a new approach that focused on interactions between elements in a system (Steinglass, 1987). Since this time, the basic principles of systems theory have been expanded and modified extensively in models of family therapy (Minuchin). "Researchers and clinicians work with families because they believe that these naturally occurring behavioral systems simply cannot be ignored. Families clearly fit the most popular working definition of a system–a set of units with relationships among them..."

(Steinglass, p. 32).

Minuchin's (1974) structural model of family functioning focused on the interaction between the individual and his or her family environment. All families fall somewhere along a continuum whose poles are the two extremes of diffuse and overly rigid boundaries. Minuchin's scheme involves family adaptation to stress and conflict. Families can respond to stress and conflict by confronting the issues and accommodating to differences, by avoiding touchy topics altogether, or by endlessly fighting the same battle. Families' ability to adapt depends on their ability to keep the boundaries of the subsystems firm yet flexible so that realignment can occur when circumstances change.

Although family therapy has long utilized these principles, failure and underachievement, were, until relatively recently, unexplored territories in the family systems literature (Green, 1989). Green believes that learning disorders (including learning disabilities) are the result of polygenetic factors including attentional



predisposition, perceptual style, memory, and temperament, and that these factors may show a wide range of outcomes depending on the constraints they impose, and on their interactions with the family and other environments relevant to the child. He believes that clinicians who limit the diagnosis only to testing of intelligence and achievement do not go far enough. In order to truly understand the nature of a child's learning disability, the practitioner must look beyond the neurological deficits a child is exhibiting in the classroom to the environments in which a child lives and learns (Green, 1989, 1990). "The family still remains the primary learning environment, the primary classroom experience, in every child's cognitive development" (Green, 1990, p. 147).

Pfeiffer, Gerber, and Reiff (1985) also argued for the implementation of familyoriented intervention with the learning disabled child, because of the profound influence
that the family has on all aspects of the child's development. They wrote, "A family
systems approach does not ignore direct school interventions, but rather serves to
incorporate such remediation within a more comprehensive system of service" (Pfeiffer et
al., p. 64). Due to the added stress of having a child with a learning disability, they
identified three interrelated levels that may cause difficulties within families: (a) the
cognitive and affective growth of the child in the school; (b) the cognitive and affective
growth of the child in the family; and (c) the psychological health of the entire family
(Pfeiffer et al., pp. 63-64). Family systems approaches recognize the reciprocal
relationship of these three levels of influences on families.

Orlando and Bartel (1989) identified two major perspectives of families that have children with learning difficulties. These two perspectives are the "pathology" or deficit perspective, and the coping perspective. The pathology perspective focuses on the



comparison of families who do have children with illnesses or disabilities with families who do not. The results of the research vary depending on the aspects of family functioning being researched, the sample on which the research was conducted, and the researcher's theoretical view of families and learning disabilities. Toro, Weissberg, Guare, and Liebenstein (1989) found that children with learning disabilities had more family background difficulties compared with non-learning disabled children. Perosa and Perosa (1982) stated that their research supported the notion that families with a child with a learning disability function more like families with a psycho-somatic child than other families. Michaels and Lewandowski (1990) in their study of boys with and without learning disabilities found that not only did the boys with learning disabilities have significantly more behavior and emotional problems that their non learning disabled peers, but their families tended to score more frequently in the extreme (disturbed) range of family functioning.

Green (1990) utilized a family systems framework in his hypothesis that information processing deficits of children with learning disabilities were maintained or amplified by deviant styles of communication (p. 145). He reported that his earlier research had discovered a significant association between parental communication deviance and children with learning disabilities. He also found that attention deficits in children were maintained or amplified by underorganized family structure (Green, p. 146). A later longitudinal study (Cherkes-Julkowski & Mitlina, 1999) into the communication patterns of mothers of young children found that mothers whose children were later diagnosed with attentional difficulties demonstrated patterns of interactions that were less



organized, and they tended to place stronger constraints on their children than mothers whose children grew up to have no identified school problems.

Margalit, Faviv, and Ankonina (1992) investigated coping, coherence, and family climate among parents of children with various disabilities and compared them with parents in a control group. Their sample consisted of, in addition to families of children with learning disabilities, parents of children with mental handicaps and emotional/behavioral disorders. They found that parents of children with disabilities reported a lower sense of coherence and an increased use of avoidant coping (i.e., efforts to deny, minimize, or escape the stressful situation). Parents also reported less emphasis on family relations and fewer opportunities for personal growth.

Other studies comparing children with and without learning disabilities (e.g., Dyson, 1993, 1996; Morrison & Zetlin, 1992; Parker, Hill, & Goodnow, 1989) found that there were no significant differences in that way in which families function. Dyson (1996) compared family functioning and sibling self-concept and found comparable results between the two groups, although she found parents of children with learning disabilities experienced more stress than parents of children without disabilities. Morrison and Zetlin compared adaptability, cohesion, and communication patterns of families with and without disabilities from both adolescent and parental perspectives. They found similar patterns of family functioning across the two groups. Parker et al. utilized Perosa's Structural Family Interactional Scale to quantify parents' perspectives of structural interaction patterns of families. They found that both parent groups had similar patterns, although parents of children with learning disabilities may have more of a tendency to be enmeshed or over involved as a result of their child's ongoing learning needs.

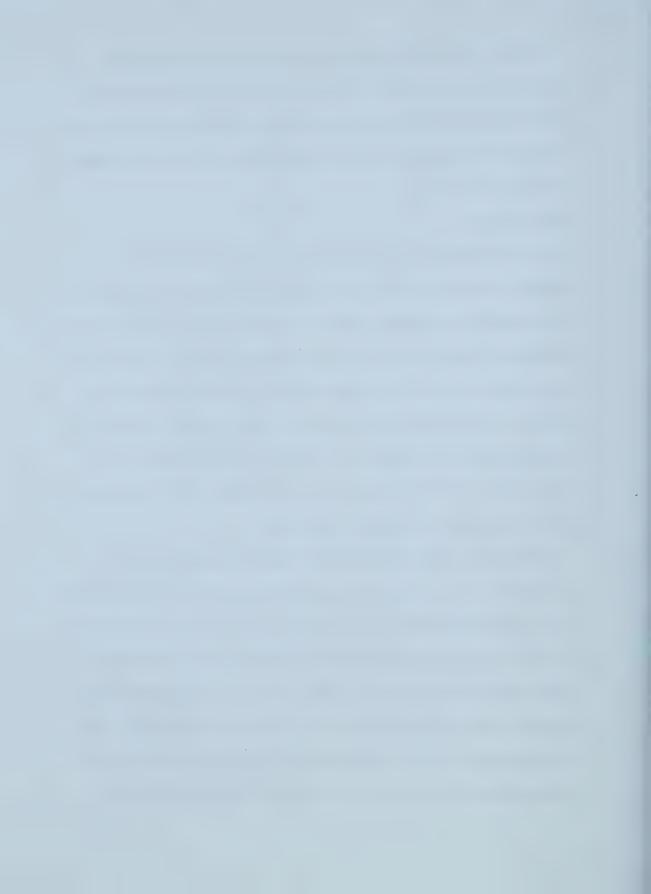


As a result of this conflicting information, it is difficult to make any specific conclusions regarding the differences between families with children with learning disabilities and those without, and it may be most appropriate to conceptualize the level of family functioning along a continuum; some families need less support than others (Pfeiffer et al., 1985).

#### Family Adaptation

In contrast to the pathological perspective, the coping perspective permits focus on strengths, not weaknesses. Rather than researching the differences between families with and without children with learning disabilities, emphasis is placed on the ways in which families adapt to having a child diagnosed with a learning disability. Research suggests that although high levels of stress are often prevalent in families with children with disabilities, families often show good adaptation (Kysela, Drummond, McDonald, Alexander, & Query, 1999; Kysela et al., 1992; McCubbin & McCubbin, 1993; McDonald et al., 1999). This adaptation is seen as the family's ability to cope with demands of having a child with unique learning needs.

Models of family adaptation developed from the ecological approach and family systems theory. They emphasize the role that the family's relationship with other social systems plays on family functioning, as well as the interactive nature of the family with each member affecting the beliefs and actions of the other members. The T-Double ABCX Model of family adaptation (McCubbin & McCubbin, 1991) views the family's experience of stress, crisis, and adaptation as a dynamic and on-going process. The model emphasizes the family's efforts to manage its demands from stressors with its resources and capabilities for meeting those demands. The family's appraisal or

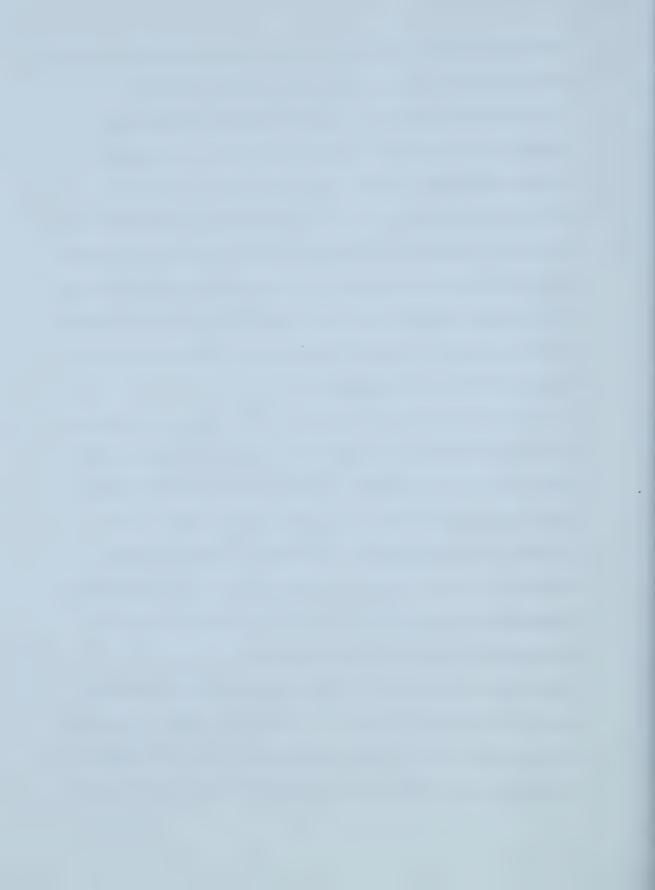


perception of the situation mediates this process. The goal is to achieve balance in family functioning, but this balance is upset by a crisis (McCubbin & McCubbin).

The T-Double ABCX Model is summarized into two phases: Adjustment and Adaptation. The Adjustment phase is characterized by the family's experience of demands, and their attempts to adjust to those demands with the least amount of disruption. These events do not always create significant hardships for the family due to their strengths, resources, and capabilities. The Adaptation phase of the model takes into account the general and specific appraisals, resources, and coping patterns believed to be critical in the family's adaptation to a crisis (McCubbin & McCubbin, 1991). This model allows the practitioner and/or researcher to consider both the presence and influence of the many variables that affect family functioning.

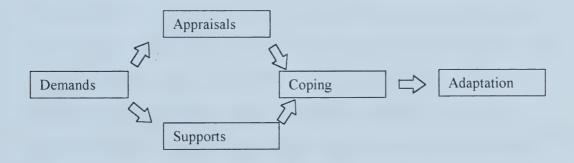
The Family Adaptation Model (FAM) simplified these characterizations of the ways in which families meet the demands placed upon them, and, like the T-Double ABCX model, has been used to describe family functioning and adaptation within families of children with disabilities (McDonald et al., 1999). The FAM identifies parental appraisals, personal and social supports, and family coping strategies as mediating dimensions between demands/stressors and family adaptation. Family coping is seen as the process of using supports and appraisals to attenuate the effects of demands and stressors on family functioning and subsequent adaptation.

An important component of the FAM is its recognition that although high levels of stress are often prevalent within families with a member with a disability, or in times of crisis, many families are showing good adaptation. McDonald et al. (1999) suggested that professionals working with families identify supports both within the family as well as



available external resources in order to establish how families deal with ongoing demands. They also suggested that it is also important to identify family appraisals (perceptions) of life events, because a family's ability to redefine or reframe a situation in positive terms contributes to their ability to cope with and adapt to a difficult situation. Coping strategies, or the behaviors that family members use to resolve conflicts, eliminate stress, and develop skills, should also be identified. To assess family adaptation, and to establish how well a family is coping with demands, stressors and daily hassles, each component is examined. The Family Adaptation Model allows the professional and the family to focus on family strengths rather than pathology or crisis (McDonald et al.).

Figure 1. Family Adaptation Model



Note. From Individual Family Planning Using the Family Adaptation Model in Developmental Disabilities Bulletin, 27, (p. 19), by L. McDonald, G. Kysela, J. Drummond, J. Alexander, R. Enns, and J. Chambers, 1999. Reprinted with permission.

Alcini (1992) conducted both qualitative and quantitative research into family functioning and family adaptations with families whose children were diagnosed with learning disabilities. She utilized the T-Double ABCX model as the theoretical foundation of her study, and found that when examining the various aspects of family



adaptation and adjustment of families with and without children with learning disabilities, there were more similarities than differences. She found that parental time and role functioning needed to be readjusted to provide for needed assistance for the affected child, as did family resources and communication patterns. She also found that social supports were utilized less by families with children with learning disabilities than the comparison groups, and concluded that this was due to these families having more difficulty acquiring social support from significant others. Overall, she found that families of children with learning disabilities were demonstrating a high level of family functioning (Alcini, p. 127).

Risk and resiliency is another perspective of family adaptation that has been examined in relationship to families with children with learning disabilities (e.g., Morrison & Cosden, 1997). The term resiliency has been used to describe the ability to manage or cope with significant adversity or stress in ways that are not only effective, but may result in an increased ability to respond in the future. Two concepts that are associated with resiliency are risk and protective factors. Risk refers to experiencing a number of stressful life events or a single traumatic event, while protective factors are the skills, personality factors, and environmental supports which contribute to resiliency (Mangham, McGrath, Reid, & Stewart, 1994).

Morrison and Cosden (1997) suggested that the presence of a learning disability is a risk factor because it impedes normal development, but that there are wide variations in emotional and social adaptations in individuals with learning disabilities and their families. As a result, the impact of personal and environmental risks on the exacerbation of difficulties must be examined along with the protective factors that ameliorate



problems. The authors reviewed the literature and identified the family to be one of the key factors that can either be a risk or a protective factor. These factors include "the personal characteristics of the child(ren) and parents, the structural characteristics of the family, and the external support available to the family" (Morrison & Cosden, p. 48). Family-Centered Practices

The term family-centered practices refers to "a combination of beliefs and practices that define particular ways of working with families that are consumer driven and competency enhancing" (Dunst, Johanson, Trivette, & Hamby, 1991). Dunst et al. summarized family oriented programs in their review of the degree of family involvement in early intervention programs. They listed four broad classes of intervention programs that consider the family as the unit of interest: professional-centered, family-allied, family-focused, and family-centered. These four classes all employ a systemic view of how the family is influenced by events within different ecological systems, but vary in the extent of family and professional involvement in decision making and intervention planning.

The professional-centered models see professionals as the experts who determine the needs of the family. Families are seen as mostly pathological or in need of help. The family-allied models view families as more capable, and enlist their involvement to implement interventions that professionals deem necessary. Family-focused models are further along the continuum in their view that most families are adapting well. These models provide a structure for families and professionals to work together to define what families need to function in a more healthy manner. Finally, family-centered models assume that families are capable of shaping the direction of resources and supports they



need, and that resources should be provided in ways that strengthen the capabilities of families (Dunst et al., 1991).

This framework of categorizing family involvement helps to clarify the varying ways that professionals view families and involve them in assessment and intervention programs. Dunst et al. (1991) found that early intervention programs were more family-focused than family-centered. I could not find any literature or research that applied this type of framework to the area of school assessment and intervention practices.

# Family Adaptation and the Assessment of Learning Disabilities

Research in the area of family adaptation suggests that in order to support the process of family adaptation, families should be encouraged to become engaged in supporting their child in a systematic way (Kysela et al., 1999; McDonald et al., 1999). The field of learning disabilities assessment has not placed as much emphasis on family functioning and adaptation as other fields of disability study, possibly because children who are diagnosed with learning disabilities are typically school-aged, and assessments are most often completed within the school, an institution that does not consistently have well established connections with the home and the family (Epstein & Lee, 1995).

Despite a lack of consistent research into specific models of family adaptation of families with children with learning disabilities, a good deal of research has been conducted into various aspects of family functioning including stress, coping, appraisals, and supports. Kysela et al. (1992) summarized the current research on families of children with learning disabilities within the dimensions of the T-Double ABCX Model. They concluded that "the focus should be on parents as intervention agents, providing them with the skills to enhance family flexibility, and training to manage demands"



(Kysela et al., p. 159). This research elucidates the need for family-centered assessment and intervention practices, and the need for parents to be central to all such interactions concerning a child with a learning disability. The following is a review of some of the current research in the area of family functioning and parental involvement during and following a psychoeducational assessment of their child with a learning disability.

# Parental involvement and the referral process.

The first step in many assessment processes is the referral which is typically made by school personnel to a school psychologist (Jackson, 1991). Many practitioners and researchers believe that it is important to engage a family whose child is diagnosed as having a learning disability right from the time of referral (e.g., Fish & Jain, 1985; Kroth, 1987). This active parent involvement can help practitioners by providing access to the parents' views of the child's developmental level and needs. A psychologist who conducts an interview with the entire family during the assessment is given additional information with which to assess the function that the learning disability has in the family (Fish & Jain). This interview process can also provide the professional with essential background information that could not be gathered through any other method.

# Parental reaction to the diagnosis of a learning disability.

Research in the area of parental reactions to the diagnosis of a learning disability is varied. Some literature describes the parental reaction to the diagnosis to be one of grieving, much like the emotional response to a death, except that the parents are grieving the loss of the idealized or normal child (Alcini, 1992; Sliver, 1988; Ziegler & Holden, 1987). Parents may show evidence of denial, refusing to accept test results, and they may become angry or have feelings of guilt. This process typically ends in acceptance of the



learning difficulty. Other researchers (e.g., Faerstein, 1981, 1986) have suggested that many parents may experience a sense of relief. Parents of children with learning disabilities often know that there is something different about their child long before a formal diagnosis is made. Therefore, when a diagnosis is finally made, many parents are relieved, because the problem is not as grave as they thought it could be. Faerstein (1986) found that there was an average of 3.5 years between when mothers first suspected a learning problem and when the disability was actually diagnosed, and that the majority of mothers described relief on confirmation of their suspicions, not defense reactions (pp. 9-10). Blumsack and Lewandowski (1997) found that the majority of children with learning disabilities had a history of neurodevelopmental problems that were identified by parents prior to a diagnosis. Faerstein (1986) reported that even though most parents were relieved, and typically accepted the diagnosis of a learning disability, they often remained confused about what the diagnosis meant, and how it might affect the lives of their children.

Models of family adaptation suggest that appraisals or perceptions of life events contribute to adaptation to a stressful event. The ability of family members to redefine a situation in positive terms, or assign positive meaning to an event, contributes to the family's ability to cope with or adapt to a stressful situation. Therefore, in addition to providing essential information regarding developmental and family functioning issues, active parent involvement will also help parents understand the learning needs of their child, as well as their child's strengths (Stoll Switzer, 1985; Turnbull, 1983; Wilchesky & Reynolds, 1986). Turnbull believes that careful dissemination of assessment results in a comprehensive, jargon free, and clear manner will help parents understand and accept the



learning needs of their child. Kroth (1987) believes that parents' limited understanding of the diagnosis is due to the reality that most professionals are not specifically trained to communicate with parents in ways that will help them deal with their children's difficulties in the most effective ways. He stated that "the most important aspect in the reporting of a diagnosis is active informing, ...phrasing messages to demonstrate interest in the patient and family, and involvement in finding solutions to their problems" (Kroth, p. 6).

Klein, Altman, Dreizen, Friedman, and Powers (1981) described four dysfunctional parental attitudes that interfere with a child's learning and behavior in a school: (1) attitude toward authority; (2) attitude towards responsibility towards learning; (3) attitude towards the child; and (3) attitude based on cultural factors (p. 15). Although the authors were not relating their model to children with learning disabilities exclusively, they discuss the importance of evaluating parental attitudes, and combining both psychoeducational support and psychodynamic counselling. Klein et al. stated, "We consider unrealistic the separation of educational remediation from the restructuring of parental attitudes that are interfering with the learning process" (p. 16). They labeled this type of intervention "psychoeducational therapy" (Klein et al., p. 16).

Silver (1988) described "Preventative Family Counselling" as the process of providing full information from the educational, psychological, and psychiatric evaluation so that parents understand their child's intellectual potential, level of academic performance, and why he or she is underachieving (p. 323). Parents are also counseled on how to be advocates for their child, and the full evaluation is shared with the child in a manner that is developmentally appropriate. In addition, siblings are informed of both the



nature of the learning disability of their brother or sister, and what the family interventions will be.

Pollak (1985) described an interesting phenomenon in his case studies of several families who had sought to apply the diagnostic label of learning disability to their child even though the assessment results were counter-indicative of it. Pollak hypothesized that this was an attempt on the part of the parents to deny the salient individual, emotional, and family systems factors at work in the school related difficulties their children were having. He also stated that some parents of children with learning disabilities may have a tendency to attribute any difficulties their child may be experiencing to the learning disability, rather than other elements in the child's environment. He discussed how this makes it more difficult to make potentially useful recommendations to the family, other than purely educational ones.

Another source of information that has the potential to contribute to parental understanding of assessment results is the written assessment report. Parents often feel overwhelmed during the feedback session, and their recall of the information may be clouded by stress that they feel (Turnbull, 1983). Often, their only source of further information is the assessment report, but this document can be confusing, and can lead to little further understanding. Cornwall (1990) reported that due to their lack of familiarity with assessment reports, parents rated them to be less understandable than professionals (e.g., teachers) did. However, parents rated the recommendation sections more favorably, and were more likely than professionals to implement the recommendations. Reports that contained behavioral descriptions combined with a lack of jargon were found to be the best format for increasing parental understanding (Wiener & Kohler,



1986). It is clear that sensitive and forthright communication of assessment findings is of great assistance to families, and that information presented in this way may enable families to adapt more easily and to foster development in their child with a learning disability.

### Parental support following the assessment.

Parents are often in need of support beyond the assessment process in order to enhance their understanding of their child's learning needs, and to help them deal with the stress of parenting a child with a learning disability (Orlando & Bartel, 1989). Once an assessment has been completed and a child has been diagnosed with a learning disability, there is often little opportunity for parents to gain more understanding of the learning needs of their child other than during the yearly meeting to review the Individual Educational Plan (IEP) or the Individual Program Plan (IPP). Stephenson (1992) found that there are two levels of communication that exist between parents and the educational system. One is the formal system, which included IEP (or IPP) meeting, reports, or annual review meetings, while the other is the more frequent, yet informal contact that parents have with teachers to discuss matters relevant to the daily functioning of their child in the class. Neither of these methods of communication provides a systematic means of support or information for parents.

Several studies (e.g., Dyson, 1993, 1996) found that parental stress is higher in families with a child with a disability. In Dyson's (1993) study of parental stress and family functioning, she found that stress levels were relatively stable both in families with a child with a disability, and in those without. However, she reported that parents of children with disabilities scored significantly higher on indicators of levels of stress than



other families, and were in need of ongoing support beyond the preschool years. In her later research, Dyson (1996) narrowed her study to parents of children with learning disabilities, and found, again, that although families were generally adapting well, there were signs of significant levels of parental stress. She attributed this stress to be a result of the child's ongoing academic and behavioral difficulties, as well as school experiences that parents considered unsatisfactory (Dyson, 1996). Most recently, Lardieri, Blacher, and Swanson (2000) found that when children with learning disabilities were divided into groups distinguishing those with behavior problems from those without, measures of parental stress were significantly different. Parents with children who exhibited both learning disabilities and behavioral difficulties demonstrated the highest levels of stress. They concluded that not all families with children with learning disabilities are alike (Lardieri et al., p. 115).

Orlando and Bartel (1989) suggested that because children with learning difficulties have been found in classrooms for many years, it is not surprising to find a range of programs available to assist teachers in managing the schoolwork and behavior of the children. "What is surprising is the lack of attention that has been given to defining alternative interventions that can be practiced within the family" (Orlando & Bartel, p. 329). Some parents may require support to help them accept a diagnosis as well as to develop more clear expectations of their child (Stoll Switzer, 1985, 1990). Faerstein (1986) concluded that support throughout the evaluation process, from referral to placement, is essential if parents are to develop enhanced understanding of their child, and to help parents deal with the stress related to both the academic and social difficulties the child experiences. Support programs for parents, although not wide spread in their



implementation, have been designed to help parents support their children both academically through homework programs, and socially and emotionally through counselling and parenting groups.

Shapero and Forbes (1981) found that support programs for parents were mostly in the form of tutoring and counselling, and that most were found to have positive effects on the academic performance of students with learning disabilities. Intervention programs designed to help parents teach or tutor their children with learning disabilities in the home have been present since the 1970s when professionals began to recognize that children learned many academic skills before entering school (Shapero & Forbes, 1981). Duvall and Ward (1997) conducted a study to determine whether parents who were not certified as professional educators provided children with instructional environments that facilitated the acquisition of basic skills. Their study compared active engagement levels and academic achievement of students who were taught at home with those who were taught by professional teachers. The results indicated that home schooled students were academically engaged about 2 1/2 times longer than public school students, and made more progress in reading and written language. Although this study was small (n=8), and no attempt was made to establish a representative sample, it demonstrated that parents can create powerful instructional environments for their children at home.

Cooper and Nye (1994) conducted a review of all of the studies exploring homework and children with learning disabilities. Because the studies examined substantially diverse aspects of homework, a narrative as opposed to quantitative synthesis of results was adopted. Although Cooper and Nye suggested that more research needs to be done in this area, they made several conclusions, including the importance of involving parents



in homework with their children with learning disabilities. Their analysis suggested that students with learning disabilities need more assistance completing tasks, and that parent training programs are needed to help parents develop tools to help establish effective, sustained homework routines (Cooper & Nye, p. 478).

Several articles outlined models of parental involvement in homework or tutoring programs aimed at capitalizing on the often-untapped resources within the home (e.g., Hourcade & Richardson, 1987; Jenson, Sheridan, Olympia, & Andrews, 1994; Patton, 1994). Orlando and Bartel (1989) described a cognitive strategy training program for parents "based on the view that many children with learning disabilities fail to deploy cognitive resources efficiently and effectively" (p. 335). They encouraged its use as a way for parents to become intensively engaged with their children in a systematic manner (p. 337). Margalit, Rochberg, and Al-Yagon (1995) described a "Home Computing Model" aimed at enabling parents to experience success and mastery in helping their children improve their learning and use of computers in their home (p. 73). Although they state that the program is still in the development stage, the model's strengths lie in its individualistic approach that recognizes that children's needs are different, as are parents' concerns and available resources. It also acknowledges that parents' stress levels change: there are times when parents may only be available to provide a supportive environment, and there are times when parents will be able to focus on meeting their child's academic needs through tutoring. All of the models emphasize the need for effective home-school partnerships for homework programs to be successful.



Kay, Fitzgerald, Paradee, and Mellencamp (1994) conducted qualitative research into parental perspectives of homework with their children with learning disabilities. Their research yielded five themes:

(a) Parents felt ill-prepared to help their children with homework; (b) parents needed more information about the classroom teachers' expectations of their child and of their own roles in helping with homework; (c) parents wanted their children to be given homework assignments that were appropriate for them as individual learners; (d) parents valued and even enjoyed hands-on homework projects in which the whole family could participate; and (e) parents wanted an extensive two-way communication system that would allow them to become partners on their child's instructional team. (Kay et al., p. 554)

This research suggests that although these parents wanted to be actively involved in effective homework activities and routines, they often felt unprepared to do so, and that limited communication between the home and school was an impediment.

Many programs for parents of children with learning disabilities have been concerned not with tutoring or homework, but with counselling. Stoll Switzer (1985) described a cognitive problem-solving model that was found to be helpful for some families of children with learning disabilities as a means of gaining insight into the needs of their children. The intent was to increase parents' factual knowledge of their children's condition, thereby decreasing anxiety and facilitating receptivity to treatment options. Seminars were held weekly and consisted of discussions involving definitions, life at home, and life at school.



Research into experiences of parents of children with learning disabilities indicates that parental concerns are not entirely academic, and that support may be needed to address emotional or social issues, not just issues surrounding school achievement.

Waggoner and Wilgosh (1990) found that many parents have significant concerns regarding the social problems of their children. Although learning disabilities are typically viewed in terms of lags in development of academic skills, parents often report that their concerns are social or emotional rather than strictly academic, because these social and emotional difficulties also complicate their children's lives in all aspects of functioning (Stephenson, 1992). Orlando and Bartel (1989) found that the critical element to the success of coping behavior in families was the level of skill demonstrated by parents in assisting their child to learn to solve problems in behavioral and social situations.

Wilchesky and Reynolds (1986) suggested that family therapy may be appropriate for some families, particularly those where the child manifests social/behavioral problems in addition to academic difficulties. Although many families may be able to adjust very well on their own, Wilchesky and Reynolds contend that the social and behavioral difficulties a child is exhibiting do not occur in a vacuum, and therefore, may be best addressed within the context of the family system. Ziegler and Holden (1987) suggested that there are three key aspects of children's development that are effected by the presence of a learning disability: self-esteem, ability to manage frustration, and sense of self-control. They suggested that family therapy is appropriate for helping parents learn to adjust their child rearing style to ensure that healthy family development occurs. These



studies suggest that parental support should not be restricted to academic areas, but social and emotional areas as well.

Silver (1988) suggested a process for family involvement when a child with a learning disability is exhibiting behavioral or emotional difficulties. He suggested that the first step is preventative counselling, so that family members learn about the nature of the identified child's learning disability, and parents learn how to become advocates for their child. If necessary, families may need to undergo additional counselling to learn how to avoid problems and assist their child, by building on a child's strengths, while helping to compensate for weaknesses. Silver proposed that parents should be encouraged to think creatively to solve problems in the home and community. Finally, in some cases, family therapy or individual therapy may be warranted. However, Silver cautioned, "Unless the child or adolescent is in the appropriate special educational program with appropriate academic therapy, any clinical interventions may be less than successful" (p. 323).

Many models of family intervention described in the literature were developed and implemented within a clinical setting, not in a school where most assessments are conducted, and where educational programs are implemented. In addition, although support programs for parents of children with learning disabilities frequently involved tutoring or counselling programs, these supports were often designed to meet the needs of the professionals, or the perceived needs of the parents: parents were rarely asked to participate actively in designing or implementing support programs (Gallagher, Beckman, & Cross, 1983).



### **Summary**

When a child is diagnosed with a learning disability it has ramifications for not only the child, but also parents, siblings, and extended family. This view of learning disabilities also suggests that the learning difficulties experienced by a child may be the product of the child's unique pattern of cognitive functioning combined with his or her educational and family environments. Parental involvement in the psychoeducational assessment of their child ensures that the practitioner has more complete background information that may result in more comprehensive and accurate assessments. In addition, parental involvement helps set the stage for greater acceptance and understanding of the learning disability, which in turn provides parents with more opportunity to utilize their strengths and resources in order to meet the needs of their child. Parental understanding and involvement may reduce stress and enhance family functioning (Morrison & Cosden, 1997). Parental involvement in tutorial and counselling programs has also been demonstrated to improve the academic achievement, emotional well being, and social skills of children with learning disabilities.

Despite research suggesting the benefits of involving parents in the psychoeducational assessment of their child with a learning disability, I was unable to find research that addresses the nature and extent of parental involvement in the assessment in non-clinical (i.e., educational) settings. In addition, parental experiences of the assessment process and subsequent diagnosis of their child have not been well examined. A more comprehensive and holistic description of parental experiences, perceptions, and concerns surrounding the assessment of their child within the school setting may contribute to more family-centered assessment and intervention practices.



#### Chapter 3

### Methodology

# Research Design

My purpose in undertaking this study was to explore the experiences and perceptions of parents whose children had been diagnosed with a learning disability. In order to accomplish this, ethnographic research methodologies were employed. Ethnographic research attempts to obtain a holistic picture of a particular society, group, institution, setting or situation. The emphasis is on documenting or portraying the experiences of individuals by observing and interviewing them and relevant others (Frankel & Wallen, 2000). In this research, the group being studied was parents, and an attempt was made to explore their perceptions and experiences of assessment as completely as possible.

O'Day and Killeen (2001) suggested that qualitative research designs are particularly relevant in the area of disability research. They stated that there has been a shift away from the view of disabilities as conditions characterizing individuals who have limited function toward a view that the disabilities that the individuals exhibit are a product of the interaction between the individuals and their surrounding. This shift has changed the questions that researchers in the field are asking, as well as the way in which the answers are being analyzed. Researchers are interested in the complexities of the human experience, and it is qualitative methodologies that help to capture them. "In the field of disability research, qualitative methodologies have emerged as some of our most important tools in understanding the complexities of disability in its social context" (O'Day & Killeen, p. 3).



In this research, semi-structured interviews were conducted to capture the thoughts, perceptions and experiences of the parents. Analysis and interpretation of the data were conducted using an inductive approach, allowing themes to emerge through the voice of participants. Wolcott (1994) stated that qualitative researchers need to be storytellers (p. 17). My goal in the data gathering and analyzing phases of this research was to collect and analyze the stories of parents whose children had been diagnosed with learning disabilities, so that I could reach a better understanding of their experiences of the assessment process.

### Research Methodology

#### Sample selection.

The Supervisor of Special Needs for a school board in Alberta (Northville) selected files of children (ages 7 to 15) who had been diagnosed with a learning disability by a school consultant. The Supervisor was asked to contact parents who, based on the information they have received, met the following criteria:

- -parents must have been legal guardians of the child for at least 5 years;
- -diagnosis of the presence of a learning disability must have been made by the consultant within 6 months of the initial contact;
- -the child who was diagnosed must be between 7 and 15 years of age (because children younger than seven are rarely diagnosed with a learning disability within a school setting, and most children are diagnosed by the age of 15);
- -there is evidence that the academic delay is not due to lack of schooling, sensory or physical handicap, English as a second language, cultural deprivation, or instruction in more than one language; and



-one or both parents agree to be involved in the study.

The Supervisor of Special Needs reported that there had been 11 children in the school district diagnosed with a learning disability since November 2000. Six of the 11 were selected for this research. The Supervisor explained that she selected the first six cases that were available (results had been reported to parents and teachers at a feedback session) when the selections were being made in mid May, 2001. The parents of these six children were contacted by telephone by the Supervisor who informed them of the nature of the study, and asked if they would be willing to participate. All six parents contacted agreed to be interviewed. The supervisor then forwarded the list to me. I contacted the parents on the list to introduce myself, to explain the study and their involvement in it, and to establish interview times. Due to limited time between the telephone contact and the first interview, consent forms could not be signed ahead of time, but were reviewed and signed by all participants during the first meeting. Although interviews were conducted with all six sets of parents, data collected from one of the parents was not utilized for this study, because it was determined that the child had originally been diagnosed with a learning disability 4 years prior to the most recent assessment.

An additional subject was added to the research from the larger urban community of Edmonton. This parent was a personal acquaintance whose child was recently diagnosed with a learning disability. She underwent the same interview process as the parents from Northville. Although it was anticipated that information gathered through her interview might be used as a comparison case, upon analyzing the data, it became clear that her experiences were very similar to the experiences of the other parents. As a result, data



collected from this parent were combined with the data gathered from the Northville parents, and were analyzed together.

### Description of the sample.

Six sets of parents were interviewed for this research. Five of the parents were from a community in Alberta (Northville), and one was from the larger urban school district of Edmonton.

Northville- Northville is the fictitious name for a small city in Alberta located several hours from any other major centers. The name of this community was not reported in this thesis in order to protect the anonymity of the research participants as well as the professionals in the community. This city had grown rapidly over the last 10 to 20 years, and had only recently developed many of the resources common to similar sized communities. Its distance from other major centers made it difficult to attract health care professionals, and had resulted in an increase in the cost of living. The population tended to be somewhat transient, and there were few long time residents of this "boom" town.

The school system in this community did not employ psychologists, but contracted to outside agencies to conduct assessments. School personnel, most typically the resource teacher, completed achievement tests, while contracted consultants conducted the intellectual and behavioral assessments. These consultants made regular visits to the community to conduct the tests and to provide feedback to school personnel and parents. The criteria used to diagnose a learning disability are outlined in the definition section of <a href="Chapter 1">Chapter 1</a> of this thesis. Five parents from this community were interviewed for this research.



Edmonton- Edmonton is a large urban centre with well-established resources. The school system that the child attended employed both psychologists and reading consultants to complete assessments. These individuals worked out of district sites and traveled to schools to conduct assessments and feedback sessions. The criteria used to diagnose a child with a learning disability are outlined in Appendix A. One parent whose child attended a public school in this school district was interviewed for this research.

Parents- Parents who were interviewed for this study all had children who had undergone an assessment within 6 months prior to the initial interview. Two of the interviews involved both mothers and fathers, while four of the interviews were mothers alone. Five of the six parents were married, and one was a single parent. Only one of the parents had another child with a diagnosed learning disability. Table 1 displays this and additional information regarding the background and demographics of the parents in this study.

Names of both parents and children have been replaced with pseudonyms:

Table 1.
Characteristics of Parents Involved in the Study

Name of Parent(s) Name of Child		Other LD Child?	Education Level	Marital Status
Christine	Matthew	No	University	Married
Darla Mack	Trent	No	Gr. 12 and trade	Married
Mitch Mack			Gr. 12 and trade	
Mollie	Bob	Yes	1 year post sec.	Married
Mary	Rachel	No	2 years post sec.	Single
Kerry	William	No	Gr. 12	Married
Suzie Garrit	Carl	No	Gr. 12	Married
Alan Garrit			2 years post sec.	

In order to understand the perspectives and experiences of the parents involved in this study, a brief description of each family follows:



Mary-Mary was a single parent of Rachel. She lived in Edmonton where her daughter attended the local school. Mary had lived in this particular community for a year, but had lived in the city all her life. She reported having learning difficulties when she was in school, and had struggled with reading as a child. She had concerns that Rachel would have the same difficulties she had experienced, but also had faith that her daughter would eventually learn to read. Mary lived close to a number of family members who were very involved in Rachel's life, and helped a great deal with childcare. Her work schedule had not allowed her to have much involvement with the school.

Christine- Christine was the mother of four children, including Matthew. None of her other children had any apparent learning difficulties, although Christine's brother had a learning disability, and although he was doing very well in life, he had struggled throughout school. Christine and her husband both worked full time, but made it a priority to work with their children and be involved in their children's lives. Christine volunteered many hours each week in her children's schools. Their family had lived in Northville for 2 years. Prior to this, they had lived in another province where Matthew had received a good deal of extra support, and had undergone some testing. Christine described herself and her family as "optimists".

Mollie- Mollie was the mother of Bob, as well as one other son who had been diagnosed with a learning disability. She was married to Desmond, and had lived in the community of Northville for 15 years. She described herself as a perfectionist and a pessimist, and explained that Desmond had much more of an optimistic view of the difficulties both boys were experiencing than she did. She explained that she had always been heavily involved in school activities, but was less involved now because of her work



schedule, and both boys being older, there was less demand from the school for parent involvement.

Kerry-Kerry was the mother of two boys. It was her oldest son, William, who was diagnosed with a learning disability as well as ADHD. She explained that she and her husband, Garth, had lived in Northville for 5 years. She reported that they often disagreed as to the severity of William's difficulties, and that she had a great deal more concern and stress than he did. She also described herself as a worrier and a perfectionist. Kerry and Garth had taken William to the pediatrician on several occasions due to their concerns that William was not completing any work at school and was difficult to manage at home, particularly with regard to homework completion. The pediatrician had apparently warned them that the teachers were just trying to medicate their son and that there was nothing wrong with him. Kerry indicated that both she and her husband had been quite involved with school activities, and had open communication between the school and home.

Darla and Mitch Mack- Darla and Mitch were both involved in the two interviews.

They were the parents of two boys. Their younger son, Trent, was the one experiencing learning difficulties, while their older son had no learning problems. Darla and Mitch reported having differing views of Trent's difficulties. While Darla felt that his problems were severe, Mitch saw them as much less problematic. Darla was experiencing a good deal of stress related to Trent's difficulties, particularly the social difficulties he was reporting. She also felt that she was taking the brunt of his frustrations as he often came home from school and exploded at her. Darla did not feel that she handled these outbursts well. Mitch stated that he felt that she just needed more patience, and that Trent



needed to learn how to deal with the children who were bothering them. The Macks had lived in Northville for 19 years, and described both active school and community involvement.

Suzie and Alan Garrit- Suzie and Alan both contributed to the interview. The Garrits had two children. Their oldest son had also experienced difficulty in school, and the Garrits voiced many concerns over the way the school had handled the difficulties. It was their youngest son, Carl, who was recently diagnosed with a learning disability. The Garrits had described some school involvement in the past, but they had had very little as Carl progressed through the grades. Alan expressed serious concerns about the school system and the capabilities of teachers, and did not agree that Carl should have been assessed. Suzie had signed the consent form while Alan was out of the country in the hopes that the assessment would suggest ways to help Carl. Neither parent felt that their son was having significant difficulties, although they described his Grade 8 year as disastrous. The Garrits had lived in the community of Northville for 24 years. Children- The children who were diagnosed with learning disabilities ranged from 6 years of age to 15 years of age, and were in Grades 1 through 9. The mean age of the children was 9.8 years while the mode was 10 years of age. All the children except Rachel attended public schools in Northville while Rachel attended a public school in Edmonton. Complete data was available with regard to the results of the intellectual assessments (WISC-III) that were completed as part of the assessment battery, but complete achievement testing was not. This was because in Northville achievement testing was completed by school personnel prior to the completion of the intellectual



assessment, and was not always reported in the assessment report. Therefore, only results from the intellectual assessments could be summarized.

The mean Full Scale IQ of the children whose parents were interviewed was 99, and all children received higher scores on the Verbal Scale than on the Performance Scale. While the mean of the children's Verbal IQs was 109, the mean of the Performance IQs was 89. Table 2 outlines the characteristics of the children whose parents were interviewed for this research.

Table 2.

Characteristics of the Children and WISC-III Results

Name of Chil	ld Age	Grade	Full Scale IQ	Verbal IQ	Performance IQ
Matthew	10	4	93	98	90
Trent	10	5	108	122	90
Bob	10	5	105	122	86
Rachel	6	1	109	114	101
William	8	3	94	102	88
Carl	15	9	86	96	79
Means	9.8	4	99	109	89

# Data collection methods and procedures.

Data was gathered through two semi-structured interviews (Appendix B) with parents of children diagnosed with learning disabilities. Parents were asked to provide detailed information regarding their experiences of their child undergoing a psychoeducational assessment through the school system. They were asked to describe their experiences prior to, during, and following the assessment. This interview process was, therefore, partly retrospective in nature in that parents were asked to recall their experiences of events that happened in the past as well as their current feelings, views, and concerns. Although parents were encouraged to tell their story at their own pace, a list of questions



was developed to guide parents when needed, and to ensure that all parents covered a similar breadth of information. The interview process and list of developed questions evolved as the research progressed, and patterns and themes emerged, as is often the case with qualitative research.

Each parent or couple was interviewed using the semi-structured interview format at a location of their choice. In five of the six cases, parents chose to be interviewed in their homes. One parent chose her place of work instead. Interviews were audio-taped (with permission, Appendix C), and transcribed by a typist or by me. The initial interviews varied in length from 45 minutes to 2 hours, while the second interviews ranged from 1/2 an hour to 2 hours. The second interview was conducted 2 weeks following the first interview so that information from the first interview could be verified and expanded upon, as well as to gather additional insights or thoughts that were omitted during the first interview. In order to accomplish this end, parents were sent a transcribed copy of their initial interview via e-mail prior to the second interview, and were asked to review it to ensure that it was accurate.

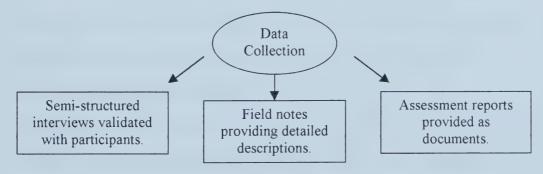
In addition to this interview format, data were gathered by reviewing the assessment report (with parental consent, Appendix D) completed by the school psychologist or consultant. This took place following the initial interview, and allowed me to have more insight into the nature of each child's learning disability. In addition, this information helped verify the information provided by the parents. For example, when parents were asked to explain their understanding of their child's learning disability, this information was compared with the assessment results in the report. Interview data were combined



with summary data from the assessment report to check for consistencies, and to enhance the researcher's understanding of the child's learning disability.

Field notes (Appendix E) were also taken as a third way to gather data. These detailed notes were written following each interview and provided low inference descriptions of the context of the interview including: the time, place, and conditions of the interview; behaviors, emotional responses, and presentation of the subjects; as well as the researchers' reactions, feelings, and understandings that emerged from the interviews. The field notes provided not only an audit trail, but also another source of information that enhanced the data gathering process. The data gathering process can be visually represented as:

Figure 2. Data Gathering Process



# Bracketing.

In qualitative research it is understood that the researcher is the key instrument, and as a result, their biases can easily influence data gathering, analysis and interpretation. In order to limit these biases, researchers must identify, or take inventory of their biases, so that they, and other readers, understand what they are, and then can consider how they may affect the research. In addition, the researcher must take steps to ensure that their biases do not contaminate the results. Bracketing is the procedure qualitative researchers



use to reduce the likelihood of researcher bias affecting results. In this research, attempts were made to limit the potency of these biases by: (a) asking open-ended questions that allowed the parents to explain their experiences; (b) gathering multiple forms of information (i.e., interviews, field notes, documents); (c) arranging a peer review of the interview data, codes and themes; (d) member checking, or validating the information and observations with the parents involved in the research; and (e) considering how my past experience might influence this study.

The following is a list of my beliefs and biases that I considered prior to undertaking this research:

- I have worked in a private practice as an educational consultant for most of my adult life. My clients have been mostly families who have children experiencing difficulties in school. Therefore, my practice has always involved parents, and my main goal was always to provide parents with the kind of information that would help them understand and support their children.
- The psychologists with whom I have worked for more than 10 years utilize a variety of therapeutic approaches, but generally work from a "family systems" perspective.

  Although I was uncertain how this counselling perspective related to the field of learning disabilities, this systemic approach was incorporated into assessments by attempting to evaluate the many influences that may affect a child's ability to succeed in school.
- In my work, I often spoke with parents who were frustrated with assessments that their children had undergone through the school system. Parents spoke of long waits for assessments, and often reported that they had little understanding of the assessment



results. I had also seen many assessment reports completed by school psychologists that provided little if any details regarding the many factors that may be affecting a child's learning.

- While working on my Master's degree, I focused many of my research projects and
  papers on assessment, and was surprised to learn of the great deal of debate regarding
  the utility of assessment practices, particularly when assessment was seen as a one-time
  event, and not a process.
- In 1999, I completed an early intervention course that promoted the use of family-centered approaches to assessment and intervention. The course also introduced the Family Adaptation Model. Although the course content was focused on utilization of this model with families of young children with disabilities, I felt that it had much broader utility. As a result, I tried to incorporate aspects of the model into my own assessment practices, by gathering more comprehensive information from parents, which allowed me to establish their strengths as well as the areas where they may need more support. Therefore, the Family Adaptation Model was already part of my professional practice.
- I am also a parent, and although I do not have a child with a learning disability, I want to be included in all aspects of their lives. In addition, it is important to me that my understanding of them, and my influence on them are both respected and acknowledged by other adults in their lives.

As a result of these professional, educational, and personal experiences, I believe that parents should be involved from the time of referral when their child is undergoing an assessment, whether that be in an clinic or a school. This involvement would not



only provide parents with more opportunity to gain information regarding the learning needs of their child, but would provide the psychologist or consultant with information regarding the child that may be essential to both the diagnosis and intervention.

However, I did not disclose these beliefs to the parents during the interview, and made a conscious effort to identify parental perceptions that both confirmed and challenged my experiences and beliefs. In addition, although I had found the Family Adaptation Model to be an effective tool when working with families in my private practice, I had few preconceived notions on how this model would relate to the families in this research, and was eager to learn how the assessment process influenced a family's ability to adapt to having a child with a learning disability.

As stated above, care was taken to first recognize areas of bias, and then to help ensure that those beliefs did not unduly influence the study. Throughout the research, I tried to ensure that I did not reveal my biases to the parents, I made conscious effort to document in my field notes those elements that surprised me or challenged my preconceived notions, and I involved peers in the review of the coding and organizing of the data. In this way, I tried to utilize my theoretical and practical knowledge of parents and assessment to enhance the research, rather than allowing it to become a limiting factor.

#### Data analysis.

Prior to embarking on the data gathering process, I began to panic as I visualized large piles of transcribed interviews stacked neatly on my desk waiting for me to organize them into some kind of meaningful information. I knew that in order to analyze and interpret the data gathered through the interviews, I needed to establish a system that would allow



me to work with the volumes of information I had collected. I had heard horror stories of graduate students weighted down under the volumes of paper their research had created. They had become immobilized and overwhelmed by the shear volume of the words, and as a result, theses were left uncompleted for months, years, or worse, forever. Because of my limited knowledge of the analysis process, and my fear of meeting the same fate, I gathered books, articles, and opinions that described in detail how the process of data analysis should occur when the data is a collection of interviews.

First of all, what I discovered was that there was no one way to analyze such data, but several sources proved invaluable as they described not only the theoretical underpinnings of various approaches, but also step-by-step instructions detailing how to put the theory into practice. Miles and Huberman (1984) described methods of data analysis that are especially useful throughout the process of data collection, because they believe that the ideal model interweaves data collection with analysis from the beginning of the research.

Analysis during data collection lets the fieldworker cycle back and forth between thinking about the existing data and generating strategies for collecting new- often better quality- data; it can be a healthy corrective for built-in blind spots; and it makes analysis an ongoing, lively enterprise that is linked to the energizing effects of fieldwork. (Miles & Huberman, p. 49)

This process of interweaving data collection and data analysis was utilized in the study. Each interview was transcribed following the first meeting. I then read each transcription while listening to the taped interview in order to check for accuracy, but also to record any thoughts, ideas, questions and interpretations. These reflective



remarks were written in the right column next to the transcription. Next, I began the process described as "decontextualization" by Tesch (1990). She suggested researchers identify in their data smaller parts or segments, but that these units of analysis must be comprehensible on their own, and should contain one episode, idea or thought. She stated that "unless you are doing the kind of analysis where every utterance or statement matters, carve out of the data only those segments that have potential relationship to the purpose of your study" (p. 18). To accomplish this decontextualization, each family was assigned a color, and data segments were highlighted in each interview. Next, the process of coding began. A peer review process was also implemented to help ensure the validity of the codes and emerging themes.

Coding is defined as the process of applying an abbreviation or symbol to a segment of words (Miles & Huberman, 1984, p. 56). Although I had established a set of tentative codes after transcribing and reading the interviews, I allowed the interviews to dictate the codes or topics that emerged. As a result, the codes changed and evolved throughout the study. When the initial interview had been reviewed and initial coding was completed, notes were made of additional areas or topics that I wanted to explore with each parent. Finally, I embarked on second interviews followed by the reviewing of transcripts, the writing of more reflective remarks, and the coding of this data. Data gathered through field notes was also coded in this manner.

Tesch (1990) described the next phase of data analysis to be "recontextualization" as it involves the organization of the data by grouping information with similar topics or codes together in order to establish patterns or themes. I utilized the index card system described by several authors (Colaizzi, 1978; Miles & Huberman, 1984; Tesch) where



each data segment was cut out and placed on an index card which identified its origin (parent interviewed and location of segment in the interview). Then, everything that belonged in one category was assembled in one place so that I could read it in a continuous fashion. The process of organizing categories and subcategories was a lengthy one, and involved a good deal of organizing and reorganizing of cards. Information within categories and sub-categories was checked for consistency, and peer reviewed to check for validity.

Although the components of the FAM (Kysela et al., 1999) were utilized when developing interview questions and when the initial codes were being established, I had not anticipated that its components would ultimately comprise the themes into which the data fit. This evolved as the categories were organized and reorganized. It became clear that parental experiences before and after the assessment naturally sorted into stressor/demands, supports, coping, appraisals and family adaptation.

Wolcott (1994) provided a clear way of describing the various ways in which researchers can work with the qualitative data they produce. He explained that the three categories were description, analysis, and interpretation, but did not suggest that they are mutually exclusive, nor did he conceptualize distinct lines between them. He suggested that the three categories could be regarded as varying emphases that qualitative researchers employ to organize and present data (Wolcott, p. 11).

Wolcott (1994) defined description as the rendering of an account that stays close to the data, with the underlying assumption that the data speak for themselves. Description answers the question, "What is going on here?" by reporting observations made by the researcher, or reported to the researcher by others (Wolcott, p. 12). Analysis is often seen



as the step beyond description, but is frequently combined with interpretation. Wolcott made a distinction between the two. He defined analysis as the identification of essential features that proceeds in a careful, and systematic manner, whereas interpretation involves going beyond analysis "to make sense of what is going on....". (Wolcott, p. 10).

In the reporting of my research findings, I strove to include all three ways of working with the data, with an emphasis on description and analysis, along with some dabblings into interpretation. However, as Wolcott (1994) warned, all data, regardless of how much a researcher tries to remain objective, are "tainted with an analytic and interpretive cast in the very process of becoming data" (p. 16). As a result, readers must assume that even in the most purely descriptive accounts, both analysis and interpretation are present.

In all of the procedures utilized throughout this study, from interviewing, to coding, organizing, and reporting, every effort was made to establish the trustworthiness of this research. Trustworthiness involves transferability, credibility, dependability, and confirmability. Transferability was demonstrated in the amount of data, in what could be called thick description. Credibility has been attempted by indicating my own background experiences, as well as through peer review and member checking. The audit trail and completeness of the documentation addressed the concerns of dependability and confirmability.

### Ethical Issues

The research proposal was submitted to and approved by the Faculties of Education and Extension Research Ethics Board to ensure that it met their guidelines. In addition, the following ethical considerations were accounted for in this study:



- 1. Informed Consent- Parents who agreed to become involved in the research were provided with a letter (Appendix F) outlining the nature of the research and their involvement in it. They were also asked to sign a consent form (Appendix C) that stated that the data gathered would be used for a Masters' thesis as well as for the publication of an article. Subjects were asked to provide signed consent for the interviews to be audiotaped, and transcribed by a typist who signed a confidentiality agreement (Appendix G). As mentioned earlier, parents were asked to provide consent to allow a copy of the assessment report completed by the school consultants to be released (Appendix D). It was clearly stated and understood that all participants could withdraw their consent at any time, and for any reason.
- 2. Ensuring Confidentiality of Research Data- Names of both parents and children were removed from all data (i.e., transcribed interviews), and no one other than the researcher and the typist completing the transcriptions were aware of their identity. Pseudonyms were given to each subject to be used for discussion of results. Names of all professionals involved with these families were also changed or eliminated, as was the name of the small urban centre in which most participants lived. This was done in order to ensure the anonymity of both the participants and professionals in the community. The names of subjects will never be used in any publications that describe the research.



#### Chapter 4

#### Results

Following the paradigm of ethnographic research, interviews had to be organized in such a way that perspectives of the parents were revealed, and essential features, common experiences, and themes emerged. This process started with coding and progressed to analysis and interpretation.

Once the interviews were transcribed and reviewed, an initial list of codes was developed so that meaningful units of information from the interviews could be identified and grouped together. This list of codes changed as the coding process progressed, but when the process was complete, a list of 27 codes was established (Appendix H). These codes reflected the types of questions that were asked and the topics covered during the interviews, as well as the type of information contained within the field notes and assessment reports. Because one of the major research questions was the affect assessment has on family adaptation, components of the Family Adaptation Model (Kysela et at., 1999) emerged as the list of codes evolved.

When all of the coding was completed, analysis and interpretation of the data began. At this point, connections between the 27 coded groups became apparent, and categories began to collapse or merge. As an exemplar of the process, one code that was used to help identify meaningful units of information was "Pre-assessment Parental Involvement" (PPI). Cards containing information that described the nature of parental involvement in school related activities were grouped together. When the coding was completed and all of the categories were grouped together, information in this category was compared with other categories. It became clear that the information labeled "PPI" was very similar to



information sorted into the category "Parental Coping" (PC), which contained parental statements regarding strategies parents had utilized prior to the assessment in order to support their children. "Pre-assessment Parental Involvement" was then included in "Parental Coping".

It was this process of data analysis, of comparing, organizing, combining, and merging categories that the Family Adaptation Model emerged as more than just a source of some of the codes, but as the source of themes that described parental experiences and perceptions prior to and following the assessment. The perspectives of the parents were not forced into this model, but gradually and naturally sorted into these categories through this process of analysis. The Family Adaptation Model provided both a parsimonious and inclusive framework to discuss the various ways in which the assessment affected parents and families.

Therefore, although it was not anticipated that the Family Adaptation Model would become the major themes or the framework for a discussion of the results, it allowed for a thorough and natural discussion of parental involvement in assessment. Pile-up stressors or demands were discussed in relation to their child with a learning disability. Parental appraisals, coping strategies, and supports were also delineated. Although the following presentation of the results divides experiences into distinct categories for ease of discussion, the lines between these categories is often blurred. For example, parental appraisals, both global and specific, affect all other categories including the degree of stress parents attribute to the demands of having a child with a learning disability as well as the coping strategies and support systems they use to deal with the demands. The discussion of the components of the Family Adaptation Model both before and after the



assessment emphasize the circular nature of family adaptation; it is not an event, but an ongoing process.

The discussion of the results of this research begins with parental experiences of the assessment and the feedback session, and then proceeds to family adaptation before and after the assessment. Although this presentation of the results does not follow in a chronological order (i.e., the discussion of the assessment occurs before the discussion of family adaptation prior to the assessment) it allows for the exploration of the affects of the assessment on family functioning to occur in a uninterrupted manner.

#### Parental Involvement in the Assessment

Parental involvement in the assessment varied little with the six families involved in the study. None of the parents was invited to participate in the assessment directly. Kerry, the Macks and Mollie all completed behavioral checklists at home, and returned them to the school to be scored and interpreted by the consultant. However, it was only Kerry who felt that it was important to meet the person who was assessing her son, and at the last minute, decided that she would stop at the school just prior to the assessment. Kerry explained her surprise at the formality of her meeting with the consultant given the impromptu nature of her visit:

In my job, I drive around town so I'm a little bit flexible.... So I told my boss, I think I need to go there.... But it ended up that I was there for like an hour. Very detailed.... And afterwards I thought, I didn't realize how important that was, and why didn't they stress to me that you should be there. Because they didn't even say you should be there.

No other parent met with the consultant prior to the feedback session.



Parental perspectives of their involvement were verified by reviewing the assessment reports and surveying the sources of background information that were contained within them. The consultants working for the Northville School District gathered a considerable amount of information from various resources including teachers and cumulative files. They also added information regarding parental concerns, but with the exception of Kerry, all other parental input was gathered second hand through teachers, school counselors, or other school personnel. Parents reported that the information gathered appeared to be accurate, although Mitch stated that because it was Darla who had had most of the contact with the school, it was her perceptions that were provided to the consultant, and not his, which were not as extreme. For all the parents except Kerry, their first direct contact with the individual conducting the assessment was at the feedback session.

All of the parents explained that they felt that it was important that they prepare their children for the assessment, but for those parent who had no prior experience with assessments, they had little idea of what was going to occur, and they did not know what to say to prepare their children. Mollie, whose previous experience provided her with more information, felt that she was able to explain the process to Bob in a manner that that ensured that his feelings weren't hurt by making it sound like there was not something wrong with him. She explained:

I was quite straightforward with him.... We knew that he was struggling a little bit and that we were trying to find ways to make it easier. We left it with that.

Just left it on a really positive tone rather than there is a problem.



Christine had some prior experience with assessment, because Matthew had undergone some school-based assessment in the past. Because she was aware that he tended to become very stressed about tests of any kind, she chose not to tell Matthew that he was going to undergo any testing. She explained, "If he has time to worry, then he gets himself all worked up, and I don't think that that is good for him. We didn't say a thing." The remaining parents had little understanding of what was going to occur, so had provided explanations similar to Kerry. "We just said you are going to be assessed and they are going to try to help you." These parents stated that they would have liked more information so that they could have prepared their children better.

#### Feedback Session

The feedback session was the first opportunity for the parents to hear the results of the assessment. Parents from Northville reported that numerous professionals attended the sessions, including the consultant who conducted the assessment, the resource teacher, the classroom teacher(s), and in some cases, the principal and a representative from the school board. Kerry and Mollie's husbands attended the meeting as well, but for the other couples, the fathers were not able to attend as the meetings were held during working hours. For Mary, whose child attended school in Edmonton, the feedback session involved the principal, the reading specialist, the teacher and herself. The psychologist who completed the intellectual assessment was not able to attend.

Parents reported generally positive feelings towards the many professionals who attended the feedback session. The parents from Northville described the consultants who completed the assessment and presented the results as caring, compassionate women who appeared to have the best interest of their children in mind. Even Kerry who



expressed a great deal of anger over the way in which the information was presented, felt that the consultant was trying her best to convey the information despite the hostile environment that erupted around her. Mary's experience was different because the psychologist who completed the intellectual assessment could not attend the feedback session due to illness, and the results were reported by the principal who read them from a brief summary report. She described the reading specialist who reviewed the achievement testing as "defensive", and the mood during the session as "uncomfortable." However, she felt that both the teacher and the principal were supportive which helped her feel more at ease.

#### Parental roles in the feedback session.

Mary, Mollie, Darla and Christine all indicated that they felt that their role in the feedback session was to ask questions, and to answer questions about their child. Mollie, who had been through an assessment with an older son, felt that she was well equipped to ask questions that would help her gain better insight into her child's performance on the tests. She said:

I ask a lot of questions. And having been through it twice makes a big difference.

I didn't need to ask as many questions this time, but I asked a lot of questions about what did you have him do, what do you mean, because a lot of the clinical headings did not mean a lot to me.

All of the other parents felt that they were unprepared to ask the kinds of questions that would have helped them understand their child better, because they did not really understand what their child had done during the assessment.



Kerry and Suzie reported that rather than seeing themselves as sources of information regarding their children during the feedback session, they saw themselves more as defendants of them. Both were overwhelmed by the number of professionals in the room, and by the formal nature of the meeting that they had not anticipated. Kerry explained that she thought that she and her husband would be reviewing the results with only the consultant, and were shocked when they walked into the room with numerous other professionals. As a result, they felt ganged up on, and that their role was one of protection or defense of their child. Kerry stated, "We always felt, and still do feel, and especially at that meeting where we got that report, ganged up on.... The title of this report from the parents' perspective would be ganged up on." Suzie described it as being "bombarded" with information. Although both these parents were appreciative of the concern of the many people in the room, they felt that it was them against the professionals.

# Knowledge gained at the feedback session.

All of the parents had gone into the assessment hoping that they would learn more about their children, and ways to help them. Only Mollie indicated that she gained a great deal of information from the feedback session. The other parents in this study felt that the results reported in this session either reconfirmed what they already knew, or did not provide enough specific answers as to why their children were struggling, and what specifically could be done to support them further. Christine explained that while there was a good deal of sharing of information during the session, the information was quite vague. Darla stated, "I guess that I expected different answers. I got a bit of guidance. I was looking for a cure." Suzie felt that she did not learn anything about Carl, and drew



the conclusion that the only thing that the teachers were having a problem with was that he was not handing his homework in, a fact that they were all well aware of before. Mary felt that she had gained little new information from the assessment. She explained, "Oh, they said verbally she was superior. They said, yes, that's about it.... They didn't mention that much. I assumed everything else was a weakness."

The parents mentioned that the test results presented to them were frequently nonmeaningful, and did little to contribute to the understanding that they had of their children. Although they indicated that they appreciated hearing that their children had done well on various areas, the scores and tests were confusing. Darla understood that Trent's verbal skills were assessed to be very strong. Darla quoted the consultant as saying "that when she did his testing his verbal skills were way up. They were like 93 or 94 or 95," but she was unclear exactly what that meant, and still did not understand why he was experiencing the difficulties he was. Even Christine, who had been exposed to test results numerous times when Matthew had undergone other assessments, felt perplexed by the scores presented to her. She described the results as "a lot of technical stuff that went in one ear and out the other." Mollie and Christine stated that they found that the graph that the consultant showed them during the assessment was very helpful because it provided a visual representation of the test scores that they found easier to understand. Mollie said, "When you see those big, big highs, and big, big lows then you know that that indicates there is an issue." Because the other parents had very little understanding of what their children had done during the assessment, and had little or no background knowledge of test scores, the results were often confusing, and appeared to provide little insight into their children's learning difficulties.



The five students who were selected for the study from Northville were referred because they were identified as having a learning disability. However, there was a great deal of confusion over this terminology. Three of the five rural families stated that there was no mention of the word learning disability during the feedback session. Darla and Suzie stated that they had no recollection of any specific diagnosis being made, whereas Kerry indicated that Attention Deficit Hyperactivity Disorder was diagnosed and discussed by the consultant. Mollie and Christine both indicated that both they and their children's teachers had used the learning disability label in the past, and that it was used during the feedback session as well. Mary, whose daughter attended school in Edmonton, reported that a formal diagnosis was not made or discussed, but explained that it was recommended that her daughter attend a program for children with learning disabilities. She felt that because of Rachel's young age, the professionals involved might have been hesitant to put a label on her. Therefore, for these parents, it did not appear that the assessment process lead to a clear diagnosis, and although the children were identified by the professionals as having a learning disability, this message was not clearly communicated.

All of the parents indicated that they would have liked to have been involved at some level in the assessment, not only to share their point of view, but to gain more insight into what actually occurred during the assessment. Christine stated, "I would like to see not just the results of the tests, but the test." Mollie added, "It would be interesting if they could demonstrate to you what they saw. What things did the kid do that made them go, 'Ahhh'." Suzie suggested that if the consultants showed or demonstrated the results rather than just told her, it would have helped her understand them.



During each of the feedback sessions described by the parents, time was spent discussing not only the results of the tests, but supports and resources that could be accessed in the school and community. For Mary and Suzie, these resources were primarily alternative programs that their children could attend in the next school year. The four other parents described how various strategies or techniques were discussed by the professionals. These parents expressed gratitude that so many people were expressing concern for their children, but they were concerned about the practicality of some of the suggestions, and they questioned the degree to which the recommendations would be carried out.

Parents in this study described only minimal involvement in the assessment process.

Only one parent met with the consultant conducting the assessment, and the parent, not the professionals, reportedly initiated this. Parental involvement for five of the six parents began at the feedback session where parents first heard the results of the assessment. Their experiences of this session ranged from supportive and informative to overwhelming and combative. Parents generally felt that they did not learn a great deal about their children, and were confused by the technical nature of the test results.

However, they were comforted to find that many of their observations were confirmed, and they felt supported by the concern shown by the professionals attending the feedback session. The parents in this study reported that a good deal of time was spent discussing recommendations that arose from the assessment, and it was their hope that these recommendations would be implemented.



## Family Adaptation Prior to the Assessment

In order to understand parents' experiences of the assessment process, I felt that it was important to gain some insight into their perception of events, their feelings, concerns, and coping strategies in relation to their child with learning difficulties before the assessment occurred. This information was retrospective in nature, but helped provide the context within which the assessment occurred, and helped understand the effect the assessment had on the parents involved in the study and on family functioning.

#### Demands.

Demands and stressors in the family are those events or situations that the parents perceived as stressful. The parents in this study described a number of stressors, concerns and demands prior to their child being diagnosed with a learning disability. These demands were not only related to the difficulties their children were experiencing academically at school, but were related to social and emotional difficulties they observed their children experiencing, and conflicts or stresses within the family due to the learning disability. In addition, parents reported that their stress level was increased due to the wait for an assessment.

Parents reported that they had been concerned about their children's school difficulties for years prior to the assessment. For Christine and Mary, the difficulties were apparent upon entering school as their children had difficulty acquiring the basic skills including letter and number recognition and various early literacy skills. For the other parents in the study, the difficulties became more apparent as their children moved through school, but revealed themselves in different ways depending on the nature of the learning disability. For example, Mollie explained that her son was experiencing difficulty learning to read



whereas Kerry stated that her son completed very little work in school, and seemed unable to put anything down on paper. For Kerry, Mollie and the Macks, Grade 2 was a pivotal year, because their children began experiencing more significant difficulties keeping up with the demands of the workload. Kerry explained how their concern for William reached a crisis point in Grade 3:

This was why we were in a crisis situation. The teacher said that he is not going to make it to Grade 4 because he can barely, barely keep up. It's only his smarts that are getting him through Grade 3. He is still smart enough to go to Grade 4, but the work load increases so much that there is no way that he is going to make it.

For the Garrits, it was not until Grade 8 that they became aware that Carl was having difficulty. They stated that they knew that he had been experiencing difficulty in math throughout school, and that handing assignments had always been an issue, but they had not been concerned about his overall progress until they were told that Carl might have to repeat the grade. Suzie explained, "Everything went wrong. He was doing really well in marks and everything until Grade 8."

Although one might assume that parents' greatest concern would be in academic areas, all the parents except the Garrits indicated that social or emotional concerns were the cause of more distress than the academic concerns. The Macks and Mollie both reported significant concerns regarding their children's social skills and the impact that it was having on them emotionally. Darla stated, "I found the social was worse.... If you don't feel like you are good socially, everything else just falls." Darla reported a great deal of distress because of the difficulty Trent was experiencing, and said that she felt powerless



in her ability to help him in this area. Kerry stated that she began having significant concerns over the effect William's school difficulties were having on his self-confidence and his self-esteem. Christine, although well aware of the learning difficulties Matthew was having in school, believed that it was his lack of self-confidence that had become his biggest obstacle. Mitch voiced similar concerns over the difficulties Trent was exhibiting both academically and socially. Therefore, it appeared that although parents were concerned about the progress their children were making academically, the social and emotional aspects that were either part of the child's learning difficulties or resulted from them, were a paramount concern.

All of the parents reported some level of concern over completing homework. Kerry and Darla reported that their families experienced significant stress as a result of their children's difficulties. Because William was getting such little work done at school, he brought volumes of work home every night, which created a great deal of stress on the whole family as the evening revolved around efforts to get William to complete his work. Kerry stated:

I even told his brother's teacher in the report card..... He is getting shortchanged at home because William takes so much of my time. And his teacher had had William so she knew exactly what I was talking about.

Darla reported similar problems when working at home with Trent. Although Trent did not bring home huge volumes of homework, when he did, conflicts would often arise.

Darla stated:

He would get frustrated because he needed help and when you would help him, he would say, 'I have to do it this way'.... A lot of times he would forget his



homework because it wasn't written on the board, or he forgot to mark it in his homework book. He didn't want to do his homework.

Christine indicated that a good deal of her time in the evening was spent helping Matthew with his homework, and that this often left the other children on their own. "As parents we try as we can, but with two of us working 60 hours a week and four kids, you only have so much time." Christine also voiced concern that her son didn't always listen to her or her husband like he did his teachers, so that helping him out was often not an easy task. These parents explained that homework was stressful because of the conflict that often arose as a result of it, as well as the time it took away from other family members.

Parents described a number of other challenges that they experienced at home with their children, but these difficulties varied with the personalities of their children as well as their own coping strategies. However, the four parents who had initiated the assessment all stated that waiting for the assessment to be completed was a source of stress for them because they felt that they would not be able to find the help that they needed until the assessment was done. Mary and Christine had both requested assessments in the previous school years, so had waited more than a year to finally hear that it would be done. For Mollie and Kerry, the wait was only a few months, and Darla had to wait only a few weeks. Darla explained that she had made it clear to the school counsellor how desperate she was, and the school counsellor was able to make arrangements to have Trent assessed quickly. Parents also reported frustrations due to long wait lists to see other professionals that they had been referred to.

Parents in this study reported a number events or situations that they perceived as stressful in relationship to having a child with a learning disability. Although concerns



regarding the academic progress their children were experiencing were present, parents reported greater levels of stress and concern over the social and emotional status of their children. In addition, struggles with homework completion were frequently reported by parents as a significant stressor in their lives. Having to spend additional time with their children with learning disabilities also was a source of stress because little time and energy was left for other family members. Parents who viewed the assessment as a means of decreasing their level of stress, reported that waiting for the assessment to be completed was an additional source of stress because they felt that they were unable to access other supports or establish coping strategies until they gained better insight into the learning needs of their children.

### Appraisals.

Appraisals are the perception of life events held by the family members that contribute to the adaptation or maladaptation of the family to a stressful event. There are both global (the view that the family members hold of life in general) and specific (the families view of events that initiated the crisis or stress). Appraisals affect all aspects of family functioning because the way in which an individual views an event has a significant impact on the level of stress and on the coping strategies and resources utilized to deal with the event. In this study, parents discussed global appraisals of life and school as well as their beliefs of what affects a learning disability might have on their children and their family. In addition, they discussed their specific appraisals of the reasons for their children's challenges as well as the meaning they assigned to their children's behaviors. Parents' understanding and expectations of the assessment process



appeared to have an impact on parental appraisals, particularly their understanding of their children's difficulties.

Although parents were never asked to identify their beliefs and values, some of their global appraisals that affected their adaptation were revealed through the interview. Both Darla and Mollie stated that they tended to have a pessimistic view of life, and felt that they were under a great deal of stress as a result of the learning challenges of their child. Both also indicated that their husbands had more optimistic or laid back views of life, and did not see their children's problems as being as severe as they did. These mothers both reported a high level of stress and a great deal of frustration.

Parents' view of the school system and school personnel had a significant impact on their involvement in the assessment process. Both the Garrits and Kerry described negative interactions with the school prior to the assessment. The Garrits, primarily Alan, had little faith in the school system. Alan was very unhappy that Carl had undergone an assessment, seeing neither a need, nor any benefits of it. Alan explained:

I do not agree with the school system here.... To me, the schools are underhanded here. They send a kid to the counsellor and try to find things out that way instead of calling the parents and talking to them. That is not right.

The Garrits' older son had also experienced some difficulty in school, and his parents had viewed the school's involvement and decisions very negatively. These beliefs and views of the school system colored the Garrits' involvement in and acceptance of the assessment process.

Kerry and her husband, Garth, also had a negative view of the school system, and this view made them more reluctant to accept the opinions offered by the professionals



involved. Kerry explained that although she and her husband were aware that William demonstrated some challenging behaviors, they felt that it was the teachers' inability to deal with him that was causing the difficulty. Kerry explained that her husband felt that it was a "female problem" because the teachers were all female and so was Kerry, and they all seemed to have more difficulty with William than Garth did. In addition, the pediatrician had told them that there was nothing wrong with their son, and that the school was just trying to have him put on drugs (i.e., Ritalin). These views of the difficulty may have made these parents more resistant to many of the interventions the school suggested.

Parental appraisals of events or difficulties affect the coping strategies they utilize and the resources they access. Therefore, parental understanding of their children's learning disabilities was likely to have significant impact on their family functioning. All of the parents in this study reported that prior to the assessment, they were uncertain as to how they should interpret their children's behaviors and attitudes. They explained that although they were aware that their children had some learning difficulties, they did not know how much of their behavior or academic struggles should be attributed to attitude or motivation, and how much was a result of factors beyond their control. Their hope was that the assessment would help them understand the reasons for their children's difficulties.

One factor that appeared to contribute to parental understanding of the assessment results was their understanding of the assessment process. All of the parents interviewed who had no prior experience with the assessment process stated that they had little or no understanding of what was involved, and although they had hopes that the assessment



would help them understand their child, they did not understand what sort of activities their child would be undergoing or what kind of information they would be receiving. Only Mollie, whose older son had undergone an assessment prior to Bob being tested, felt that she was prepared to explain the process to her child, and was prepared for the kind of information that she would be receiving once the results were shared with her. Mary explained that even though she had requested that an assessment be done, she was not aware of what was involved. She reported:

I knew about the testing, but I wasn't prepared for the I.Q. test. You know, maybe I.Q. is even a bad word for it, but that's what they said.... They didn't tell me.

They just said psychological assessment. I thought, why?

Mary added that she did not feel that she was prepared for the feedback session and she did not know what to expect. She explained, "I didn't even know what they did. I didn't know what to ask. Usually I bring in a list of questions, but I really didn't know what to expect." All parents suggested that it would have been helpful to have some information ahead of time as to what their child would be undergoing so that they could prepare for both their children and themselves for the process.

Parental appraisals, both global and specific, effected how they viewed the problems their children were experiencing as well as the coping strategies and support systems that they put in place. Parents who had a more pessimistic view of life in general, seemed to experience higher levels of stress, and reported more negative feelings and fears surrounding their children's struggles. Those parents who had negative feelings regarding the school system, appeared to resist the interventions and views of the school personnel involved with their children. Parental understanding of the nature of their



children's learning difficulties affected how they coped with the challenges, and the meaning they assigned to their children's' behaviors. The understanding of the assessment results and acceptance of them appeared to have been effected by parents' previous experience with assessment, and how well they understood what occurred during the assessment. Although most parents in this study looked forward to the assessment, they had little understanding of what would occur. This made it difficult to understand the assessment results, and made it difficult for them to prepare their children. Therefore, parents' understanding and expectations of the assessment process appeared to have an impact on how much the assessment contributed to positive family adaptation.

### Coping.

Coping strategies are behaviors that family members use to resolve conflicts, eliminate stressors, and acquire and develop skills. Parents in this study revealed a wide range of coping strategies. Supporting their children at home with their homework, and attempting to teach them social or problem solving skills, were discussed. All of the parents also discussed their involvement in school activities and communication with teachers as one of the most important strategies that they used to ensure that their children's needs were being met in the school, and to help them understand their children better.

Although parents discussed the many frustrations they had surrounding homework completion, they all discussed attempts they had made to structure homework time in order to support their children with learning disabilities as well as the other children in their family. Christine described how she and her husband had established a specific time for all of their children to complete their homework, and if they had none, to play or



read quietly. Kerry described the many strategies that they had attempted to help William complete his work. Although all of the parents described attempts to support their children at home, they described ongoing frustrations. Despite attempts to develop effective coping strategies around homework, their children were still struggling, and battles surrounding homework continued.

Additional coping strategies reported by parents included providing emotional support for their children and attempting to teach them social and problem solving skills. Mary described how she tried to create balance in Rachel's life by not dwelling on her schoolrelated difficulties and by stressing all of the capabilities she had. Kerry explained that she and her husband made efforts to use positive reinforcement with their children, and although it was difficult to find behaviors to reinforce at times, they felt that trying to focus on the positive rather than the negative would help William's self-esteem and his behavior. Mitch reported that he frequently coached Trent on how to deal with other children who were bothering him, and although he was uncertain how well Trent was able to put this advice into practice, he felt that it would eventually have a positive impact on Trent. Mollie described her attempts to protect her children from the negative reactions of others. She said, "As a parent of kids with learning disabilities, I find myself being quite overprotective sometimes because you want to protect your kids from negative reactions from other people." These parents made efforts to help their children develop effective coping skills, and tried to buffer the affects of their social and academic struggles.

When the parents became aware that their children were having difficulty, they coped by communicating these concerns with teachers, school counselors or the principal so



that reasons for the difficulties could be explored and strategies could be put in place.

When Kerry became frustrated with the volume of homework that William was bringing home, she made contact with his teacher in order to find a solution. She stated:

In Grade 3, we were having two hours of homework. We would go to the teachers and say, 'We cannot handle this,' and they would say, 'That's way too much for his age. He should only be doing 20 minutes.' So we tried that for a while.

This involvement allowed parents and teachers to work together to solve problems that the children were encountering both at home and at school.

Mollie discussed another benefit of her involvement in the school. She explained that by being a constant presence in the school, she felt that it was more likely that school personnel would follow through with interventions. She stated, "I think it helps that they know me really well. I've done a lot of volunteering at the school, so they know me, they know my character and personality and stuff. I think that they are a bit scared of me."

The parents who were most heavily involved in volunteering for school activities and in the classroom felt that this involvement allowed them a better understanding of how their children were coping on a daily basis in school, and allowed them to gain a better understanding of their child's difficulties. Christine and Mollie both reported that they had spent many hours a week helping out with various school activities and therefore had gained a good understanding of their child's learning needs. Although they stated that they had chosen to be involved, at times it was an additional source of stress because they could not deny the kind of difficulties their children were experiencing. However, this



involvement allowed them a solid understanding of their children's difficulties. Christine explained the benefits of her involvement:

From the time he was in Kindergarten, I have volunteered 10 to 20 hours a week in the schools, so I have been very involved, and I have known from day one what his problems were, and if anything we need more ideas of how to help him. As to what the actual problem was, it wasn't a big surprise.

Darla and Kerry had reported that they had regular contact with the school, but had not spent as much time in the schools. Both mothers indicated that they did not feel that they had clear understandings of why their children were experiencing the difficulties they were.

Parents in this study reported utilizing a number of coping strategies in order to resolve conflicts and eliminate stressors caused by having children with learning difficulties. These coping strategies included establishing homework routines, teaching problems solving and social skills, providing emotional support, and ensuring regular contact with teachers and other school professionals. Despite the presence of many coping strategies, parents continued to feel that they did not have the tools to help their children, and were hopeful that the assessment would provide them with information and strategies that would enhance their skills.

# Supports.

Supports include resources within the community, school or extended family that the family is aware of or has utilized in order to help maintain a reasonable level of health and to help deal with the demands placed upon them. The supports may be formal (e.g., services provided in the school or community, support groups, churches or religious



organizations), or they may be informal (e.g., extended family, friends, or co-workers). The parents in this study were asked to identify supports or resources they were aware of, or were available to them prior to the assessment. Their responses indicate that parents were accessing many resources, both formal and informal, prior to the assessment, but were hopeful that the assessment would help identify more such tools, as well as to help them establish which resources might be more appropriate for their children.

One of the formal supports reported by parents was services within the school setting. All of the parents indicated that their children were receiving some kind of assistance or support prior to the assessment. All of the children from Northville had some degree of involvement with the school counsellor or resource teacher, and modifications had been made in the classroom to help support their child. Mary, whose child did not live within this school district, indicted that the teacher had been very supportive, and along with helping Rachel in the classroom, had recommended vision and hearing tests prior to the assessment. Despite the availability of these resources, parents still felt that their children's learning needs were not being met.

With the encouragement of school personnel, or due to their own concerns, Mollie, the Macks, Kerry and Mollie identified other formal resources they had accessed. Mollie had pursued the assistance of an occupational therapist to help Bob with his writing skills, the Macks enrolled Trent in a private math program because he was struggling with basic facts, Kerry had repeatedly sought the advice of her pediatrician due to her concerns regarding William's difficulty with work completion and concentration, and Christine had enrolled Matthew in a Sylvan Learning Centre to help develop his reading skills. These



parents reported varying degrees of success with these resources, but all indicated that they needed more support.

In addition to these formal supports, parents also discussed informal supports such as family members, friends and co-workers. Support from spouses was mentioned by all of the married couples, and although they reported that differences in points of view was a source of stress, all indicated that being able to discuss difficulties and having another individual to share the parenting responsibilities were valued by them. Friends, family members and coworkers were also mentioned as sources of emotional support and ideas. However, Mitch expressed concern over Darla's tendency to share her concerns with others outside their immediate family. He stated, "Trent is our trouble, not the neighbors." Darla explained her need for support outside their immediate family, "My niece used to do that, and her mom kept doing this, and it worked. I'll try it. You are just grasping for something to try." Mollie discussed a close circle of friends that she used as a sounding board, while Kerry reported that her husband's family had been a source of both information and support.

Despite active school involvement and access to resources in the community, all of the parents except the Garrits felt that they needed more information and better direction. As a result, the Macks, Mollie, Christine, and Mary all initiated the assessment. Although Kerry was not the one who initiated the assessment, she reported that she jumped at the opportunity to get more answers:

(We) didn't know where to turn because the doctor says he's okay but the school says he's not. We know there is something wrong here, so we didn't know where to turn. So we jumped at the assessment.



For the parents who requested the assessment, all reported that they had to repeatedly push to get the assessment done, and that they felt that it was their persistence that ensured that it was undertaken. Mollie described her involvement as "the squeaky wheel gets the grease." These parents recognized that their children were struggling with various aspects of their lives. Their hope was that the assessment would provide them with a diagnosis, or at least with the kind of information that would enhance their understanding of their child, and lead them to effective interventions or strategies.

The Garrits experience was quite different. Although they had recognized that Carl had had some difficulties in the past, they felt that he was doing well in Grade Nine, and stated that the first they had heard of an assessment was in March of the current school year when Suzie was asked to sign a paper consenting to the assessment. Alan was out of the country at the time, and was very angry that she had consented to the assessment. Not only was he unaware that Carl was having any difficulty, he did not see how the assessment was going to have any positive impact on Carl. He stated clearly, "If that was up to me, it would have never been signed in the first place."

The five parents who viewed the assessment as a positive resource, all expressed some degree of relief when they were notified that the assessment would be done, but along with the relief, there were also feelings of concern that the difficulties might be more extreme than parents had thought. Mary explained, "I thought, what if they find out she was totally..... You know what I mean. She doesn't have anything nice... there is no brain whatsoever or something." Darla, on the other hand, who felt that she was getting the brunt of Trent's frustrations taken out on her, was fearful that the assessment would turn up nothing. She stated, "I was scared that they weren't going to find what I saw."



Christine, although relieved that the assessment would be done, had no concerns because she felt that she already had a good understanding of where Matthew was at, but was hopeful that the assessment would reveal more directions for interventions.

Parents in this study described access to both formal and informal supports prior to the assessment. All reported that their children were receiving help within the school. Other formal supports within the community were being accessed by some of the parents. All described receiving informal support from family, friends, and co-workers. Despite access to these varied resources, most felt that they needed more specific information regarding their children's needs in order to direct resources more effectively.

### Family adaptation.

Family adaptation is an ongoing process of adjusting to the demands of daily life. It is the net result of the coping strategies, use of support systems, colored by global and specific appraisals. The families in this study began to recognize that their children were experiencing difficulty upon entering school, or at some point later on in school when either teachers began pointing out that their children were falling behind, or it became clear to them as a result of their child's academic progress or behavioral or emotional difficulties at school or at home. All of the families described feelings of stress as a result of the challenges that their children were experiencing. The degree of stress appeared to vary with the parents' global appraisals (eg., pessimistic versus optimistic), as well as the kinds of difficulties their children were experiencing. Parents reported greater concern over the social and emotional difficulties their children were experiencing than their academic struggles. Although the parents described various coping strategies and access to various formal and informal support systems, five of the



six parents felt that they needed additional information in order to help their children cope more effectively in and out of school.

Families in this study revealed varying levels of family adaptation. Although it could not be measured directly because no measure of family adaptation was administered, it was clear that parents were making efforts to adapt to the demands of having a child with a learning disability. Three of the parents described situations prior to the assessment that suggested that they had reached a crisis point. Darla, Kerry and Mollie all described high levels of stress and frustrations because the strategies they had tried did not appear to be working, and the supports their children were receiving did not appear to be adequate. Darla and Mollie sought an assessment in their attempts to find more effective solutions. Kerry welcomed the assessment, although she had not initiated it. It was the hope of these parents that the assessment would lead to more answers, and more solutions.

The Garrits, Mary and Christine described some level of stress as a result of their children's learning difficulties, but did not appear to be in a state of crisis. The Garrits had some concerns over their son's school difficulties and tried to support him by ensuring that his homework got completed and by reminding him to hand it in when he got to school. Because they did not see his difficulties as being severe and they did not trust the school system, they did not feel that an assessment was necessary. The Garrits lack of involvement and contact with the school may have contributed to their apparent limited awareness of the extent and nature of Carl's challenges. Therefore, although they may have felt that they were coping well, they may have been blind to the struggles their son was having.



Mary and Christine discussed a number of concerns that they had for their children, as well as numerous coping strategies and supports systems that they had in place. They both described themselves as optimists, and although they had concerns that the schools their children attended may not be able to meet all of their needs, they reported a positive outlook on their children's lives despite their academic struggles. They explained that they hoped the assessment would provide them with more information, but described effective coping strategies, support systems, and positive family adaptation.

The parents interviewed for this research all described how they were attempting to adapt to the challenges of having a child with a learning disability. How well they were adapting depended upon a number of factors including the kinds of difficulties their children were experiencing, their beliefs and values, as well as their coping strategies and ability to access both formal and informal supports.

## Post-Assessment Family Adaptation

The preceding information provided by the parents was also retrospective in nature; the parents were recalling information and feelings that had occurred from one week to five months prior to their interview. The following information was gathered to gain a better understanding of how the parents were coping once the assessment was complete in order to establish what aspects of their lives they felt were altered by the assessment.

#### Demands.

Prior to the assessment, the parents involved in the study had indicated that they were experiencing a number of stressors due to the difficulties their children were experiencing in and out of school. Following the assessment, all of the parents indicated that the stressors remained similar if not the same, although for some, stress was relieved because



they had documentation that there indeed was a problem, and they had a better understanding of what the problem was. Kerry described the most significant drop in stress levels. Following the assessment, she and her husband decided on a trial of stimulant medication for William, hoping that it would help him focus his attention so that he would accomplish more work in class. The medication had almost an immediate impact on him, and he began completing his work at school. The battles over homework did not disappear, but "they were just not as bad and not as much." Even though Darla felt that not a lot had yet been done for Trent and that his social and emotional problems were still present, she reported lower levels of stress due to her enhanced understanding of her son's difficulties, and her ability to reframe some of his behaviors in a more positive light. She stated, "I don't know if he is just not lashing out or blowing up as much, or if I just notice things differently." Mary suggested that she felt better knowing that Rachel was going to get some help. Mollie felt that the information provided to her helped her understand what Bob's difficulties were. She explained, "Knowing. Confirmation of what I knew has relieved some of the stress."

The Garrits indicated that their level of stress might have increased as a result of the assessment. They did not express a great deal of concern over Carl's academic progress at the time of the assessment, and were shocked at the mention of learning problems. In addition, the assessment appeared to cause some tension between Suzie and Alan. Suzie had agreed to the assessment while Alan was away, and Alan was angry that Suzie had agreed to it. For the Garrits, the assessment may have been the cause of more stress, at least until they were able to see that Carl might receive assistance at school that he would not have received had he not had the assessment.



One of the most prevalent concerns discussed by parents following the assessment was that the recommendations would not be implemented, particularly those regarding social supports in and around the school. Darla, Mollie and Christine all corroborated that although the recommendations discussed in the feedback session and provided in the report seemed appropriate, they were uncertain that there was enough personnel to carry them out, or that they would be carried out with any consistency. Christine described her frustration over a reading program that was discussed at the feedback session. She explained, "Some of the ideas that were thrown out. I have been rather disappointed, because they have been axed already." Mollie voiced her concern that without constant monitoring, the teachers may not follow through with the strategies that were discussed. "I think that unless I continue to push it, nothing is going to happen." Therefore, even though parents perceived many of the recommendations as appropriate, they did not have faith that they would be implemented consistently.

The Macks, the Garrits, and Kerry expressed a good deal of confusion as a result of conflicting information that had received from professionals. The Macks had taken Trent to see a psychiatrist who had suggested that Trent exhibited signs of ADHD as well as a nonverbal learning disability. It was their understanding that this was not what the school consultant had found when she had conducted her assessment. Kerry also had taken William to see a psychiatrist who said that he showed signs of Tourette's Syndrome. The Garrits were confused when they read the report that suggested that Carl was not a candidate for a special program, yet his teachers were recommending it. They were also angry that that term learning disability was being used because it had never been used to describe Carl's difficulties. This lack of consistency made it harder for the families to



understand their children's difficulties, and made it harder to access appropriate resources. As a result, parents reported that their level of stress remained high following the assessment.

All of the families described some changes in the demands and stressors following the assessment. Although some stress was relived because difficulties were identified, stresses often remained because there was confusion over the specific diagnosis, and there were concerns that the recommendations would not or could not be implemented. Kerry reported the greatest decrease in her level of stress, whereas the Garrits indicated that their stress level might have increased. Overall, there appeared to be a shift in stresses for most families as most reported ongoing concerns and stresses following the assessment related to their children's learning difficulties.

## Appraisals.

There appeared to be some shift in appraisals as a result of the assessment process for all of the families involved, but to varying degrees. In terms of specific appraisals, parents described how they had gained some additional insight or understanding of the reasons for their children's difficulties. This changed their view of the reasons for their children's behaviors. This increased understanding also lead to more opportunities to change their coping strategies. However, parents reported little change in a more global appraisal including their understanding of what a learning disability is and the affect that it may have on their children's life. Their limited understanding of learning disabilities might have made it harder for them to access appropriate supports.

The most significant change in specific appraisals appeared to occur with Kerry and her husband who came to the conclusion that William did indeed have ADHD, and



placed him on a trial of medication. Not only did they change their view of the difficulty their son was having, but their view of the teachers and other professionals involved. Kerry explained, "I was too harsh on the teachers because they really pushed us. I think looking back... maybe we needed to be pushed. Maybe that was their job." Kerry explained that it was a comment made by one of William's teachers as they left the feedback session that was the turning point. Kerry quoted the teacher as saying, "I hope that your fears do not cost William." This statement, along with reading the information in the report, changed Kerry and her husband's appraisal of the difficulties William was having.

The five parents who had looked upon the assessment as a positive support, indicated that they had hopes that the assessment would help them gain insight into the reasons for the difficulties their children were experiencing in and out of school. This certainly appeared to the case for Kerry who felt that the assessment had provided a perspective of William's difficulty that she needed to have. All of the other parents indicated that although the assessment may have provided them with some added information in terms of strengths and weaknesses, they felt that they were still in the dark as to why their children were struggling. Even though Alan did not feel that he had gained anything from the assessment, he reported that he had understood that Carl "falls in the lower middle bracket.... He is not right out to lunch." Christine explained what she had learned from the assessment, "Again, we are very informed as to where he is at, but not how to get him to the next level." Mary described the impact that the assessment had on her understanding of Rachel's learning difficulties:



I don't really understand what they put on the assessment besides the fact that they told me what I already knew. She has everything there, it is just for whatever reason it's not coming together.... I would like to know more, why or what exactly is happening or where the focus of the problem is. It just seems so broad, but I also know that this is an age where things are very broad.

Mollie and Darla both felt that the explanation that was provided to them regarding their children's difficulty with sequencing provided them with some insight into the reasons for their children's challenges.

Parents' view of what a learning disability is appeared to change little; parents who had little understanding of the term prior to the assessment, seemed to have no better understanding following the assessment despite the fact that their children had been identified as having a learning disability. Mollie, Christine and Mary all had prior experience with the terminology. Mollie had another child who was diagnosed with a learning disability, Christine's older brother had a learning disability, and Mary had learning difficulties when she was a child. These mothers seemed comfortable with the label, and provided a definition of it that indicated at least a basic understanding. Mary stated that:

A learning disability is when someone doesn't fit into the average population. I think we have a lot of different ways of learning and so we tend to be average.

The majority of people learn in certain ways. So when someone doesn't fit into that, that's a learning disability.

Christine explained her understanding of a learning disability:



I suppose if you are doing IQ tests and you find out you have a pretty smart person that just can't seem to pick up this thing that everybody else gets by a certain level, then that would be a learning disability.

Mollie articulated her understanding as:

I would say that there is a huge discrepancy between performance and skills. You can demonstrate that the kid has an above average intelligence or something, but their performance academically can, at times, during certain activities, be very poor.

These parents indicated that not only were they comfortable with the terminology, but understanding what a learning disability is and is not, helped them understand their children better and provided them with some direction in their quest for additional resources and support.

The parents with no prior experience of the term learning disability indicated much less of an understanding, and as a result, frustration over where to turn for help. Both the Macks and the Garrits expressed anger that I had used the terminology during the interview. Both stated that their children were not "disabled". Darla stated, "I don't know if I am just old fashioned or what. When you were talking about disabilities earlier, that bothers me." Alan said, "But to tell somebody that they have a disability and not identify exactly what it is, that's wrong. All it does is tick everybody in the family off." When asked what they thought a learning disability was, Darla stated, "When you have a disability everybody sees it wherever you go." Alan described someone with a learning disability as "someone that's slow." Kerry, who had no prior experience or knowledge of the term, defined it as "anything that interferes with them being able to learn," but had no



idea what the distinction was between ADHD and a learning disability, and was not aware that William might have a learning disability. Following the interview process, the concept was explained to all the parents who had limited understanding of the label. All of them were very appreciative of the information and stated that they felt more comfortable with it. All of these parents also explained that they would try to seek out more information and supports for the children, and that understanding that their children had learning disabilities might help them in this regard.

All of the parents provided insight into their specific appraisals of how they viewed their children's current challenges as well as their more global outlook on life through their statements regarding their hopes or concerns for their children's futures. The Garrits, who had few concerns with Carl's current achievement, saw few limitations, and were certain that he would learn a trade. Christine had no fears about Matthew's future, stating, "Matthew will be happy whatever he is doing." Mary indicated more ambivalence in her outlook, explaining, "If I look at the future of course, you see the two kids. One getting the masters degree and you see the other going, 'Do you want fries with that.' So we were hoping for the masters." Darla, Kerry, and Mollie, who tended to worry more and described themselves as both perfectionists and pessimists, had more concerns for their children's futures. Darla's level of concern was illustrated through her statement, "I don't want him to be so frustrated that in 5 years he will go and take a gun to school and blow this kid's head off."

Parental appraisals, both global and specific, affect all aspects of family functioning because the way in which an individual views an event has significant impact on the level of stress and on the coping strategies and resources utilized. For example, if



parents attribute their children's behavioral or academic difficulties to laziness or attitude, their strategies would likely be different than parents who attribute the challenges to neurological or physiological problems beyond their control. One specific parental appraisal that appeared to change little for most parents as a result of the assessment was how parents viewed the learning difficulties their children were having. Although Kerry reported significant changes in her understanding of the reasons for her son's difficulties, others reported only small increases in their understanding. In addition, parental understanding of learning disabilities, a more global appraisal, appeared to change little as a result of the assessment. Changes in appraisals or how parents viewed the reasons for their children's challenges affected coping, access to resources, and family functioning.

## Coping.

Parents in this study described their hopes that the assessment would provide them with information that they would be able to utilize to help their children. Despite parental concerns that the assessment information was somewhat incomplete and that they felt that they still needed more answers, all of the parents described instances that suggested that the assessment provided them with some enhanced coping strategies. Parents described how the need for involvement in, and communication with, the school had been reemphasized through the assessment process. In addition, all of the parents described a continued emphasis on homework routines, and a desire to improve this often-frustrating family activity. Mollie, Kerry, Darla and Mary, also all mentioned that their increased understanding of their children's difficulties had resulted in more patience with their children so that they did not become as frustrated as often. Although the parents



indicated that the assessment did not address their needs specifically, some changes in their coping strategies were apparent.

Parents discussed that they would continue to be in close contact with school personnel in order to ensure that their children's learning needs would be met, and that the recommendations provided were followed through. Even the Garrits, who had very negative feelings about the assessment process and the results, were eager to attend a school function where the program Carl was placed in was being introduced. Mary had already visited the new school Rachel would be attending, she had met the teacher, and learned all about the program that would be provided. Mollie, Darla, Christine and Kerry all stated that they would be in regular contact with the school, and would be certain to meet with the new teachers in the fall to discuss their children's learning needs. For Mollie, although this involvement was important, she was trying to establish a balance that would allow her to be involved, without be being over-involved. She said, "I am a worrier and a perfectionist so sometimes it is good not to see every little thing that happens.... For me, sometimes a little less involvement is a good thing."

Only Kerry reported significant changes in their homework routine as a result of the assessment. William's new ability to focus in class had reduced the amount of work he brought home significantly, and although his mother still reported he had difficulty completing what he did bring home, the volume was greatly reduced, and so was their level of stress. All of the other families reported continued struggles with homework. The Garrits stated that Carl still struggled with handing in assignments, Mollie continued to closely monitor Bob's homework, Christine remained uncertain how to support Matthew besides reading with him nightly, and Darla and Mike stated that although they



tried to support Trent at home, it remained a daunting task. Mary indicated no changes in her routine with Rachel, but indicated that next year in her new, homework was part of the program, and they would need to adjust their lifestyle in order to keep up with the anticipated volume.

Kerry, Darla and Mollie all reported that a better understanding of their children's challenges had lead to more patience and less frustration. Mollie stated, "I don't know if my strategies have changed much, but sometimes understanding goes a long way to ease frustration." Darla reported that although she felt that she had few effective coping strategies when it came to dealing with Trent, her new understanding had improved her coping:

I think sometimes that when he frustrates me and I want to say something, I'll remember that he can't take five directions and instructions.... You have to stop every time and consciously think that there are problems and I have to give him a little rope.

None of these parents felt that they coped well with their children all of the time, but that the knowledge that there was a disability and that their children were not intentionally doing things to irritate them, eased these mothers' frustrations. Therefore, changes in appraisals made it easier for these parents to cope with the ongoing demands of having a child with a learning disability.

Parents reported that they were utilizing other coping strategies to help support their children emotionally and socially. Mitch described how he continued to coach his son through his social difficulties, and Darla described how she and Mitch were trying to provide opportunities for Trent to express his feelings. She explained:



I think he was frustrated the other day. He talked to me about it. We were laying in bed talking about it and then Mitch came in from some place and Trent says, 'Dad, can I have a conversation with you?' He wanted to see if he had any ideas about his frustrating day.

All of the parents also reported how they felt it was important not to dwell on their children's struggles, but to find as many opportunities to have fun and get away from stress. This relieved their children's level of stress as well as their own.

Parents reported that the assessment provided them with few specific strategies to help them deal with their children, but they continued to make efforts to enhance their coping strategies. They described continued involvement in the school lives of their children, and they maintained their focus on homework routines despite continued frustrations with this aspect of daily life. They also described how they tried to support their children emotionally and socially, and that they made efforts to minimize the impact of their learning disabilities by focusing on their strengths and involving themselves and their families in other activities that did not revolve around their children's difficulties. One coping strategy most directly effected by the assessment was the increase in patience and understanding reported by most parents. They explained that the awareness that many of their children's difficulties were the result of real learning problems allowed them to reframe how they viewed some of their children's behaviors and difficulties, which provided them with added patience and empathy. This change in appraisal changed parental coping strategies.



## Supports.

Parents in this study all had reported that they had some awareness of and access to formal supports in the school and greater community prior to the assessment being completed, as well as the informal supports of friends, families and co-workers. However, they felt that these supports were not enough, or that they needed more direction as to which resources would be most appropriate. All of the parents reported that as a result of the assessment, more school resources were discussed and that in some cases, referrals to outside agencies were suggested. Many of the parents also pursued other resources on their own as a result of the information they received. Half of the parents in this study felt that the report was an important document that not only helped them understand their children's challenges, but helped guide their pursuit of additional coping strategies and resources to help meet these challenges.

The purpose of assessment from the perspective of school personnel is to provide information in order to guide intervention and/or program placement, and as a result, much of the focus of interventions revolved around school related activities. All of the parents, including the Garrits, felt that the assessment did provide additional suggestions that could help their children in school. These suggestions included segregated placement options, accommodations including the use of keyboards and exam accommodations, and various strategies to enhance academic and/or social skills. Although parents reported that they often had concerns that the recommendations would not be carried out, they expressed relief that school personnel were willing to try new approaches.



All of the parents indicated that they not only saw schools as a resource for their children, that the school personnel were an important ongoing resource for them. All of the parents identified various professionals within the school as individuals they would turn to to seek additional information or advice. Mollie stated that she would first approach teachers because "they are the biggest source of information." Christine felt that the principal not only knew her child well, but was an excellent source of strategies and resources. Mary also felt that the school principal was a good source of information, but had indicated that her attempts to get more information from the reading specialist had not been well received. Although the Garrits did not have faith that school personnel were making the best choices for Carl, they suggested that they would pursue other options within the system if they did not feel that the program in which he was placed was appropriate. These parents clearly felt that it was school personnel who could provide them with kind of ongoing information and support they required.

Parents reported a number of resources that they had become aware of either through the assessment or as a result of their pursuit of more answers and more supports.

Although most of the families had indicated that they had accessed several resources prior to the assessment, the consultant or school personnel involved recommended other resources. For example, Kerry described a workshop that she had attended on the recommendation of the school counsellor that was presented by the local Health Unit.

She explained that a pharmacist had discussed the use and affects of medication for ADHD. Kerry stated that both she and her husband had found it very informative, and it eased many of their concerns over the use of drugs. Christine reported that the principal had recommended that Matthew become involved in some extra-curricular activity where



he could be given a chance to excel. She explained that she and her husband had enrolled him in Tae Quan Do and had noticed a difference in his self-esteem. The Macks had tried counselling for Trent through Mental Health, but had not found it beneficial. They were considering how they might be able to find a "big brother" or mentor for Trent. Mary stated that it was her aunt who provided her with ongoing support and encouragement, and although she was aware that there were likely a number of other supports available in her community, she was uncertain as to what they may be.

Half of the parents felt that the report was a valuable source of information in their attempts to support their children. All of the parents except the Macks had received a copy of the assessment report prior to the initial interview. Molly, Kerry and Darla stated that they would review the report regularly in order to guide them to the appropriate resources, and to show to other professionals who may become involved with their children. Kerry felt that the report provided a thorough and accurate view of William that allowed her to gain a better perspective of the difficulties he was having. She planned to share this information with future teachers and professionals, if the need arose. Mollie felt that the report was very specific and accurate, and although she found the reliance on words without any visual representation (i.e., graphs) more challenging to understand, she appreciated the concrete nature of the numbers that were able to quantify some of her son's difficulties. Although Darla and Mitch had not seen the report until the second interview (it was provided to them with permission from the Director of Special Needs, because they had not received it in the mail yet), their first impression was, "I think it specifically identifies areas enough that we can gear in that direction and start doing something specific instead of just a general problem and where do you start." For these

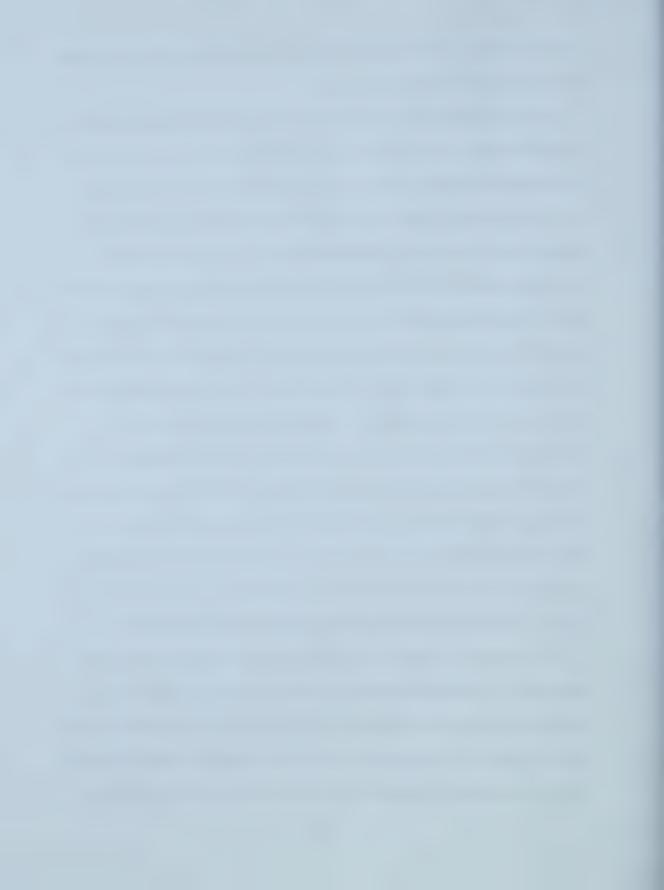


parents, the concrete and more specific nature of the report was a valuable asset to them in their search for both answers and support.

In contrast, Christine, Mary and the Garrits did not feel that the report provided any helpful information. One factor that may be contributing to this perception was that all three stated that they did not feel that the individuals who conducted that assessments really understood their children, and the report did not increase their knowledge and understanding of their children. Christine felt frustrated because Matthew resisted undertaking tasks that he perceived as "babyish" despite his need to work on some basic skills. When asked what she felt when she read through the recommendations, she replied, "How on Earth am I going to get him to do this." Christine, Mary and the Garrits all agreed that they would not likely refer to the report for their own guidance, and would not likely share it with future teachers. Mary stated that she understood that the information would be part of Rachel's file anyway, and that it may be used as a comparison to any future assessments. Alan stated that he saw no value in the report, and chastised the writer for its length, while Suzie felt that she may read through it in the future to see how Carl is doing in comparison to what they predicted. Overall, therefore, although some parents felt that the report was a valuable tool and applauded its detail and specificity, others felt that it did not provide them with any useful information.

Parents reported few changes in the informal supports they received following the assessment. Kerry said that she felt that her husband was more of a support to her following the assessment because his view of William's difficulties was more in line with her own. Families and friends continued to be sources of support for many of the parents.

Darla continued to seek the support and advice of her friends and family, and Mollie



described how she and her co-workers often spent breaks discussing the ongoing challenges of parenting. Mary explained that her parents provided a great deal of support in terms of childcare, but did not believe that Rachel had a learning disability. As a result, they were not supportive of the interventions she was pursuing. Mary explained that it was her aunt who supported her attempt to get help for Rachel.

Mollie and Darla both expressed one prevalent emotion in relation to support and resources; loneliness. Although they both recognized that there were a number of people, including professionals, friends and family that were available and willing to help, they felt that ultimately it was all up to them. Mollie stated, "That's how I feel. I feel very alone in this process." Darla corroborated that sentiment with her statement, "I figure that the weight is all on our shoulders to get him there" when describing her desire to find solutions to Trent's struggles. None of the parents in the study had much faith that school personnel had the time or the resources to meet their children's needs, and ultimately it was up to them to monitor their children's progress. For Darla, even though she had been looking for the magic pill to solve all of Trent's difficulties, she realized that there was no pill, and the solutions would only come through her family's ongoing efforts.

# Family adaptation.

Family adaptation is an ongoing process of adjusting to the demands of daily life. The question of whether or not the assessment and subsequent diagnosis contributed to family adaptation to these demands cannot be addressed specifically, because no measure was used to quantify this type of data. The broader question, "What impact did the assessment have on family adaptation?" can only be examined by addressing the various components of the family adaptation model; demands, coping, supports and appraisals. The parents



interviewed for this research reported a number of demands associated with raising children with learning disabilities. They also described various coping strategies and an awareness of and access to a number of support systems and resources. These stressors, coping strategies and supports were mediated by their appraisals of life in general and of the learning needs of their children. Although some parents reported higher levels of stress prior to the assessment than other parents, each family was attempting to adapt to the demands of having a child with a learning disability.

Despite minimal involvement in the assessment process, and the perception of only small gains in information by most parents, parents utilized the assessment information to the best of their ability in order to allow ongoing family adaptation. The parents in this study demonstrated to varying degrees that the information they received changed some of their appraisals, altered some of their coping strategies and increased their awareness of resources available to them in the school and community. As a result, parents reported some decrease in stress levels following the assessment. However, the demands of having a child with learning difficulties remained due to the parental concerns regarding the availability of resources in and out of the school, the need for more effective coping strategies, and the many unanswered questions regarding the nature of their children's learning difficulties.

Kerry, Darla and Mollie all reported that they felt that the assessment had helped them deal more effectively with their children, and although Kerry and Mollie still felt that they had many questions left unanswered, they felt that the assessment had been a valuable tool, and that their lives were better as a result. Kerry stated:



And they even wrote on his report card, 'You're on your way, William.' And we went from the point of William is not going to make it to Grade 4 to William's going to Grade 4 and he's going to do great.

Darla felt that her family was still under a significant amount of stress, and although not a great deal had changed since the assessment, she was hopeful that they would be able to access resources that would help. She was aware that her high levels of frustration and poor coping skills had a negative impact on Trent and their entire family, and indicated that she would look for ways to enhance these skills. Mollie explained that although her coping strategies had not changed significantly, validation of her perceptions of Bob's struggles as well as a better understanding of the nature of his difficulties had decreased her stress levels.

The Garrits and Mary both reported that the assessment had little impact on their family functioning as neither their appraisals nor their coping strategies had changed as a result of the assessment. However, both indicated some relief that their children would be placed into programs that were developed to provide extra support. Mary looked forward to Rachel's new school and the intensive help they promised to provide. Although Suzie and Alan indicated that the assessment caused them more stress and concern initially and they had some reservations about the new program Carl had been placed into, they stated that they were eager to learn about it, and would be satisfied if it looked like it would help their son. Christine, who felt that she had a good understanding of Matthew's needs before the assessment, did not feel that the assessment had changed anything for her or her family, and only hoped that the recommendations for strategies to be implemented at the school would help her son.



Despite limited direct involvement in the assessment, parents in this study utilized the information that they were provided with to adapt to the ongoing challenges and demands of raising a child with a learning disability. Although some parents were overwhelmed at times by the numbers of professionals involved in the process, they all stated that they appreciated the fact that there were many individuals who were attempting to assist their children. Unfortunately, minimal involvement in the assessment process, and parental perceptions that they did not receive enough meaningful, specific information regarding the needs of their children may have limited or impeded family adaptation and adjustment. For parents in this study, many questions remained unanswered.



### Chapter 5

#### Discussion

The purpose of this study was to explore parents' experiences, concerns, and feelings surrounding the psychoeducational assessment of their child with a learning disability. To accomplish this goal, an ethnographic research design was employed where parents were interviewed and were asked to describe their experiences before, during and following the assessment. The data gathered through this process was analyzed in order to gain insight into the impact this process has on families and their ability to meet the ongoing demands of having a child with a learning disability. Researchers suggested (e.g., Dyson, 1996; McDonald et al., 1999, ) that families with children with learning difficulties may experience higher levels of stress than other families, but are generally demonstrating good family adaptation. This research demonstrates that despite little involvement in the assessment process, and reports of limited understanding of the assessment results, parents utilized the information they received in order to facilitate ongoing family adaptation. The following is a discussion of how this research compares with previous research in the field of learning disabilities and parental perspectives. The discussion revolves around the four major research questions:

# What are Parental Concerns, Feelings, and Expectations Prior to the Assessment?

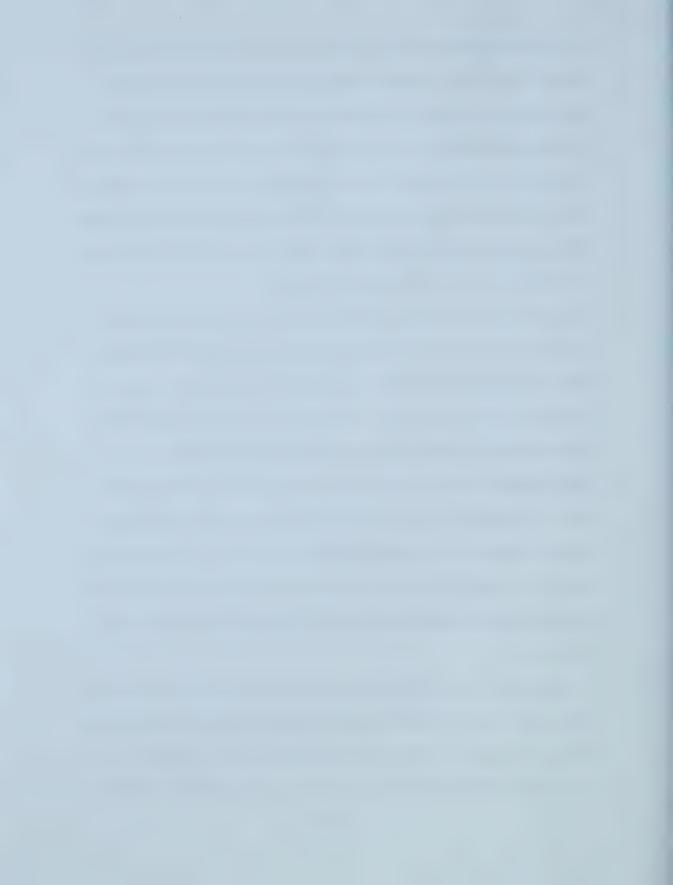
Parents reported concerns with regard to the academic difficulties their children were experiencing in schools, but as other researchers have suggested (e.g., Stephenson, 1992; Waggoner & Wilgosh, 1990) parents were more concerned with social and emotional difficulties, because these difficulties affected all aspects of their lives. Stephenson stated that professionals and parents may have very different views of what learning disabilities



are. He said that parents tend to stress social and emotional aspects of learning problems, whereas teachers focus on academics. Half of the parents interviewed for this study reported feelings of considerable stress when they observed or heard about the poor interactions their children had with other children in and out of school. In addition, all the parents reported some level of concern over the emotional strain that the learning or social problems were having on their children. Therefore, this research corroborated that although parents have concerns regarding the academic progress of their children, social and emotional concerns are often seen as more critical.

An additional source of stress reported by all of the parents except the Garrits was waiting for the assessment. All of the parents had concerns about their children long before the assessment was completed, and they reported waiting anywhere from a few weeks to a few years for an assessment to be completed once it was requested. The parents who looked favorably upon the assessment indicated this wait as a source of stress. Faerstein (1986) found that there was an average of 3.5 years between when mothers first suspected a learning problem and when the diagnosis was actually made. The specific amount of time was not established in this study, but it was apparent that parental stress increased as they watched their children struggle, and they waited for an assessment to help them establish why this was occurring and what could be done to support them.

Cohen (as cited in Alcini, 1992) found that the time prior to the diagnosis is when parents agonize over what might be causing the problem. In addition, Cohen found that the longer the waiting period prior to determination of the problem, the more likely it is for the parents to feel a sense of relief just to have the problem identified. These two



factors were also found in this study. Parents reported that they felt both fear and anxiety prior to the assessment as they agonized over what the results might reveal. Some parents felt fear due to their worries that the problem might be bigger than they had thought. Darla was concerned that nothing might be found to help explain the difficulties her son was experiencing. Of the five parents in this study who looked favorably upon the assessment, all indicated some sense of relief that the assessment was going to occur. They also felt relief that a problem was identified, even though a specific diagnosis was not made.

This study identified another source of stress caused by the wait for the assessment not identified by Cohen (as cited in Alcini, 1992). Parents stated that prior to the assessment they felt they did not understand the reasons for their children's difficulties, and that they may not be able to help them until the assessment was complete. The longer they waited, the longer that they felt that they were in a state of limbo.

# What are Parental Perceptions of Their Role in the Assessment?

Jackson (1991) suggested that it is school personnel who typically make referrals for assessments to a school psychologist. However, four of the six parents in this study reported that it was at their own request that the assessment was undertaken. I was unable to find any other research to verify if this was typical of assessments involving children with learning disabilities, or whether this phenomenon was unique to this study.

Alberta Education (1996) maintained that assessment is an integral step in the process of meeting the needs of children with learning difficulties. They outlined a multi-step process of gathering information and implementing and evaluating strategies, and suggested that this process begin pre-referral, or before a formal assessment is instigated.



They also indicated that it is a collaborative process, and that parents, teachers and other professionals should work together at all times. This model suggests that if the interventions do not prove to be effective, then a referral should be made to a student support team.

Five of the six parents in this research indicated that they discussed their concerns and strategies regularly with teachers prior to the assessment. Although parents utilized a number of different coping strategies, involvement in, and communication with school personnel was reported as a means of gaining insight into how their children were functioning in school, and it provided an opportunity for parents to share their perceptions and concerns with teachers. Although the term "support team" was not utilized, the four parents from Northville who reported frequent communication with teachers, also described involvement of other school personnel (e.g., resource teacher) as a means of providing additional assistance. The assessment, therefore, occurred after some level of intervention in the school.

Stephenson (1992) previously observed the type of communication and contact with school personnel that parents reported in this research. Stephenson stated that there are two levels of communication that occur in the schools between parents and school personnel- the formal and the informal. While the formal system includes IEP meetings and annual reviews, the more frequent is the informal system where parents and teachers discuss daily concerns. Although regular contact occurred between the home and school, this communication was not systematic or scheduled, but occurred on an as-needed basis, instigated by both teachers and parents, often at times of crisis. However, parents reported that this communication was crucial to their ability to support their children, and

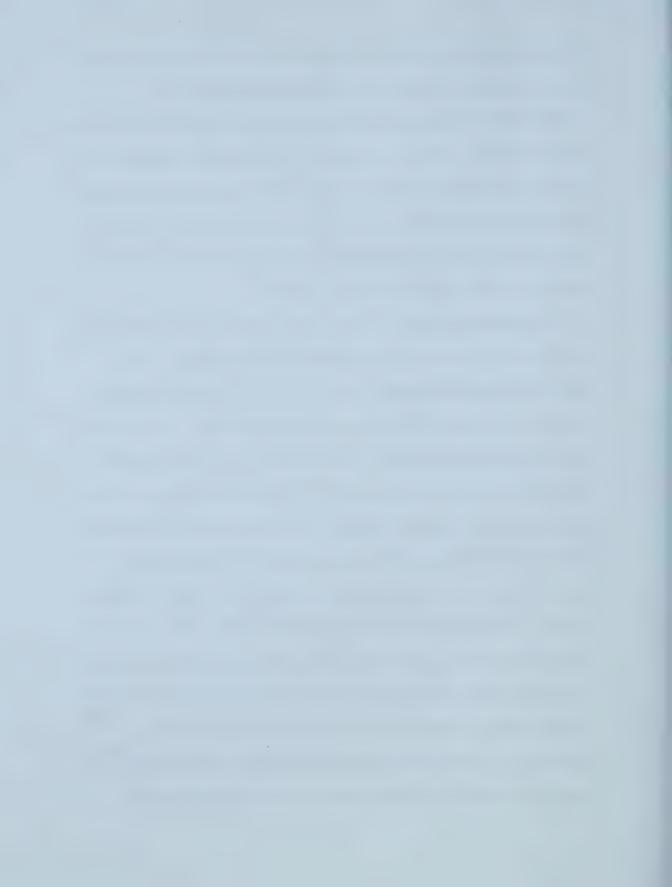


that teachers were often the first person that they would go to in order to discuss their concerns regarding the day-to-day issues that arose in their children's lives.

Sattler (1990) described norm-referenced tests, interviews, observations, and informal assessment as the "four pillars of assessment" (p.3). Although there is disagreement as to what instruments should be used, and the degree to which norm-references tests versus more curriculum related measures should be utilized (e.g., NcMamara, 1998; Fish & Jain, 1985), there is general agreement that the various components of the assessment need to be weighed carefully in order to make a diagnosis.

The assessments described by the parents and documented in the assessment reports in this study involved norm-referenced tests, some interviews of teachers (or at least information gathered from teachers), and on one occasion, a classroom observation. However, only one parent (Kerry) in this study was interviewed prior to the assessment, and she met with the consultant due to her own initiative. This does not suggest that information was not gathered from parents, but that the information utilized was gathered second hand through teachers or counselors. Three of the parents completed behavioral checklists that allowed them to provide some insight into their perspective of the problems, but they were not interviewed directly regarding their concerns. In addition, no informal assessments appeared to be utilized by the consultants, although they may have been used by teachers prior to the assessment. This suggests that the all "four pillars of assessment" may not have been involved in the assessments described in this research.

Dunst, Johanson, Trivette and Hamby (1991) divided the degree of family involvement in intervention practices into four broad categories: professional-centered, family-allied, family-focused and family-centered. The category that appears to



characterize the involvement in the assessment process described by the parents in this study may most appropriately be described as family-allied. Although the families were involved in the feedback sessions, they described their roles as sources of information regarding their children, or as recipients of information. The consultants discussed the results of the assessments as well as some of the recommendations. Parental input was not requested prior to the assessment, but the professionals involved did enlist the help of the parents to implement some of the interventions. Therefore, although parental involvement appeared to be viewed as an important component of the assessment process, the process described by the parents in this research was guided by the professionals who determined what might be best for the child.

## What are Parental Experiences of the Feedback Session?

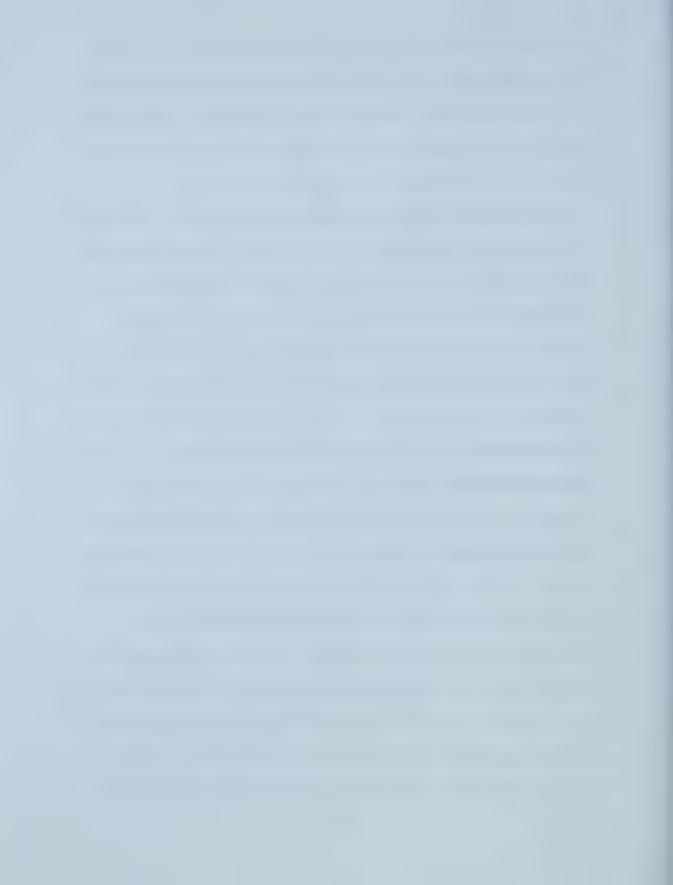
Turnbull (1983) believed that careful dissemination of assessment results helps parents understand the learning needs of their children. Only Mollie, who had prior experience with assessment, felt that she learned a lot from the feedback session. Not only were parents uncertain of the diagnosis, but they had difficulty understanding the assessment results. Kroth (1987) believed that the reason that parents are often left with a limited understanding of the diagnosis is that professionals are not trained to communicate with parents in a way that will help them deal with their children's difficulties. Parents from Northville reported that they felt that the consultants who reported the results were caring, supportive individuals, but that they had difficulty understanding the technical nature of the results. Mary, whose daughter attended school in Edmonton, felt that the results were reported to her in a defensive manner, and that the consultant involved had poor rapport with her. Parents who were provided with the



WISC-III results in the form of a graph said that they found this format more helpful. They also said that they would have been able to understand the results better if more of the tests were shown to them. Although Kroth stated his opinion that professionals were not trained in how to communicate effectively with parents more than a decade before this research, these results suggest that his stance may still be accurate.

Parents also reported feelings of being unprepared for the assessment. Those with no prior experience with the assessment process were uncertain of what was going to occur during the assessment, and did not know what to expect from the feedback session. This lack of understanding made it difficult for them to prepare their children for the assessment, and made it difficult for them to prepare themselves for the feedback session. Kerry and Suzie were overwhelmed by the formality of the feedback session, and felt that they were being ganged up on as they sat in a room with many professionals. I could find no research to confirm or dispute whether these parents' experiences were typical or not. How Does the Assessment and Subsequent Diagnosis Affect Family Adaptation?

Research suggests that although high levels of stress are often prevalent in families with children with disabilities, families often show good adaptation (e.g., McDonald et al., 1999). This study confirms this stance. Although parents described a good deal of stress due to the academic, emotional and social difficulties their children were experiencing, they were showing good adaptation. Parents had developed some effective coping strategies, and they were accessing many resources to deal with these difficulties, but were striving to find more information in order to understand the reason for their children's struggles. The assessment was seen by most of the parents as a means of providing information that would help them support their children more effectively



Appraisals.

Researchers (e.g., McDonald et al., 1999; Stoll Switzer, 1990) suggested that parental appraisals have a significant impact on family functioning. McDonald et al. discussed the importance of professionals understanding the global and specific appraisals of the parents with whom they work because these appraisals or beliefs influence coping mechanisms parents utilize, as well as the support systems they will access. Because most parents in this study did not meet with the consultants who did the testing until the feedback session, it is unlikely that these professionals had the opportunity to gain insight into parental appraisals. Although parents indicated that both global and specific appraisals affected how they dealt with their children's difficulties, this research suggests that the assessment had little impact on global and specific appraisals.

One specific appraisal that appeared to change little as a result of the assessment was parental understanding of the specific nature of their children's learning disabilities.

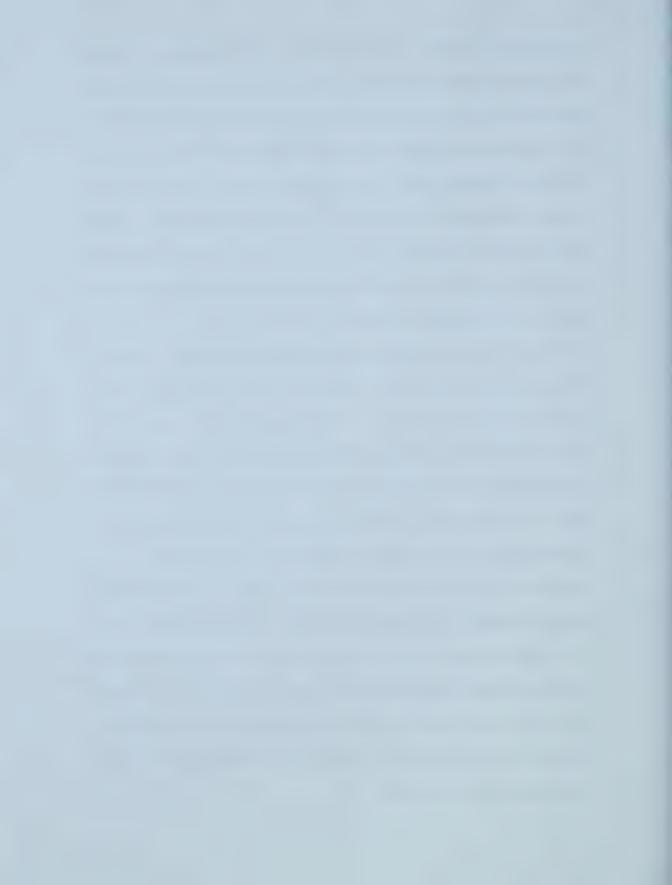
However, most parents reported that the understanding that their children did have unique learning needs resulted in them having more patience with their children as they were able to attribute some of their children's struggles to learning issues rather than attitude or motivation. Because confusion regarding the specific nature of their children's learning difficulties persisted, few significant shifts in these specific parental appraisals were apparent.

Parental understanding of the term learning disability appeared to change little as a result of the assessment that their children underwent. Parents who went into the assessment with limited understanding appeared to have no better understanding when



the assessment was complete. Their knowledge of this concept appeared to be related to previous experiences with the term. I was unable to find other literature that addressed the affect assessment has on parental understanding of learning disabilities, but Stoll Switzer (1985) suggested a model of intervention with families in which the first step is to help parents understand what a learning disability is before discussing concerns and strategies. This program was designed due to the understanding that parents who had a low level of understanding of the diagnosis were more likely to have expectations that were out of line with ability, and were less likely to accept interventions supports they accessed, and their acceptance of their children's learning difficulties.

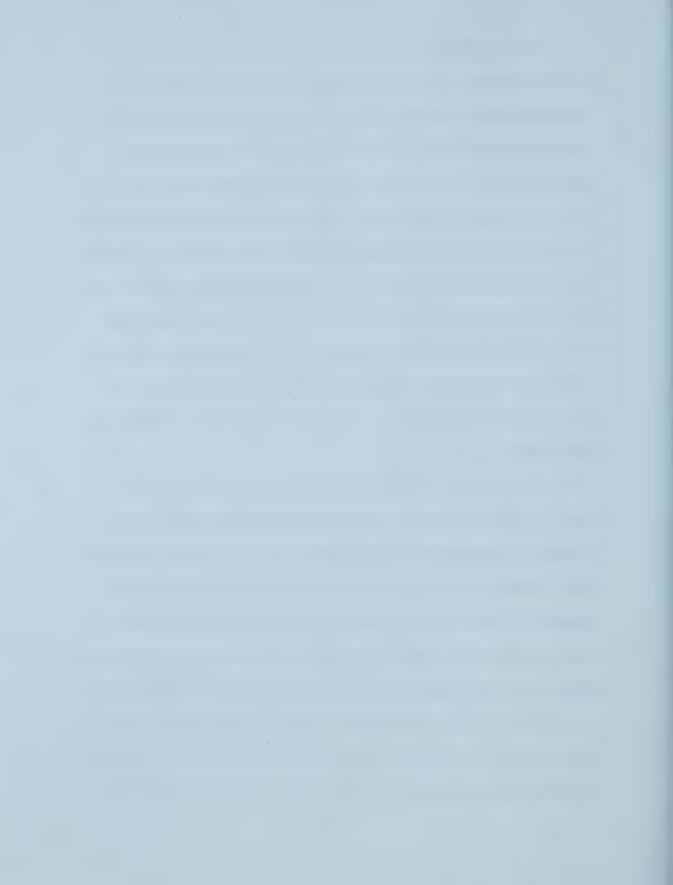
While some literature suggests that parental reaction to the diagnosis of a learning disability can be one of grieving (e.g., Silver, 1988; Ziegler & Holden, 1987), others suggest that parents may undergo a sense of relief (e.g., Alcini, 1992; Faerstein, 1981, 1986). Faerstein (1986) found that even though most parents were relieved, they often remained confused about what the diagnosis meant. In this study, only three of the six parents interviewed recalled that the term learning disability was used when the results were being reported, and none of the parents felt that they had gained a clear understanding of the specific nature of their children's difficulties. Therefore, feelings of neither grief nor relief were not reported in this study. Although most parents were relieved that their concerns were validated and strengths and weaknesses were identified, they remained confused about what the actual diagnosis was. Alcini (1992) found that because parents already knew that a problem existed, they wanted something more definitive than a general description. She found that for the participants in her study, a specific diagnosis was of great value.



### Stressors/Demands.

Lardieri, Blacher, and Swanson (2000) suggested that parents with children who exhibit both learning disabilities and behavioral difficulties experience higher levels of stress than parents of children who have learning disabilities, but no significant behavioral problems. This differentiation appeared to be present in this study as the parents with children who were acting out at home or at school described greater levels of stress than the other parents. These parents expressed a need for more than just academic support for their children, but opportunities to develop better coping strategies for both them and their children. The need for ongoing support for the emotional and social difficulties is well documented in the literature as several models are proposed to deal with both enhancing parental understanding of the learning needs of the child, and helping the family develop effective coping strategies (e.g., Silver, 1988; Zeigler and Holden, 1987).

In addition to the stress of feeling the burden of responsibility for their children, parents described the ongoing concern for their children's futures. These concerns appeared to be related to the parents' appraisals of life and of their children's difficulties. Those parents who viewed their children's difficulties as minor, or whose previous experience had a positive outcome, saw few limitations placed upon their children's futures. Parents who viewed their children's difficulties as extreme and appeared to view life in a more pessimistic manner, expressed greater concern over their children's futures. Alcini (1992) found that mothers of younger children (7-10 year olds) appeared to be most concerned with socialization with peers, while parents of 11-13 year olds tended to express more long-range concerns about their children's ability to be self-sufficient,

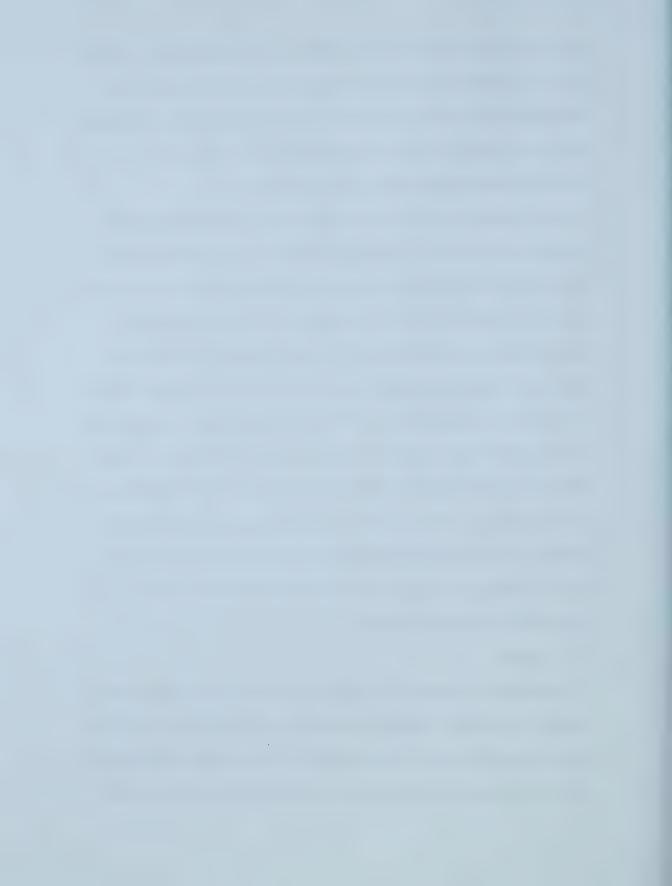


happy adults. This study did not find this differentiation. Parents of children with both learning and social or emotion difficulties expressed concerns about their children's future ability to relate to others or their self-esteem and emotional status, while parents whose concerns were more strictly academic had concerns regarding how long they would need to monitor and support their children in school.

One of the most prevalent demands reported by parents both before and after the assessment was the stress on the family as a result of the struggles with homework, because they felt that the coping strategies that they had developed to help support their children at home were not effective. This perspective was corroborated by Kay, Fitzgerald, Paradee, and Mellencamp (1994) who studied parents of children with learning disabilities and found that parents often felt ill prepared to help their children with homework. Although many models of homework support exist (e.g., Hourcade & Richardson, 1987; Jensen, Sheridan, Olympia, & Andrews, 1994; Orlando & Bartel, 1989; Patton, 1994) these parents felt that they were on their own to establish homework routines and strategies. Because the focus of intervention was mostly school-based according to the parents is this study, all but one parent reported that their homework routines had changed little, and that they would like more information on how to cope more effectively during homework time.

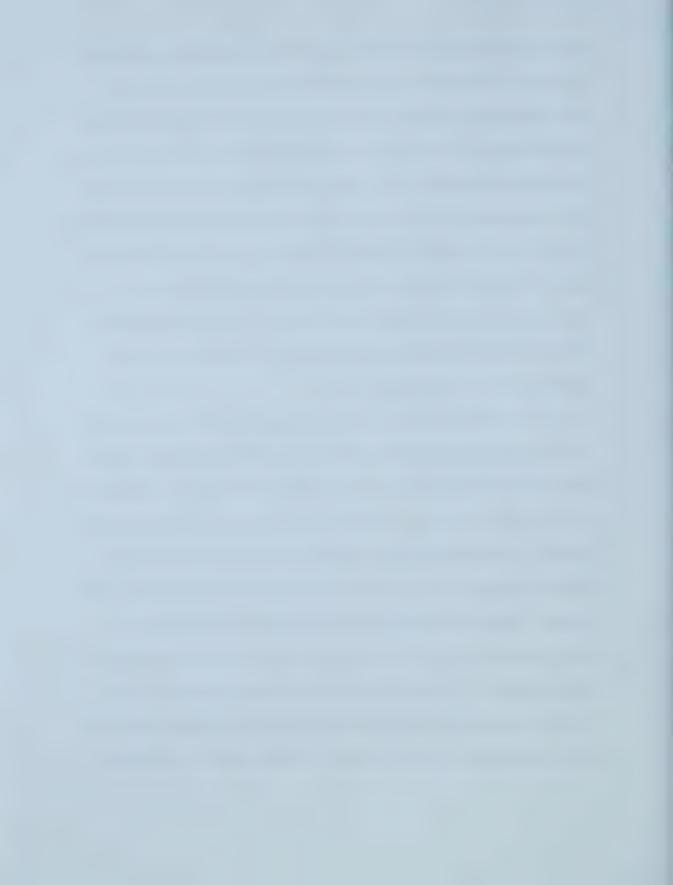
## Coping.

Despite parents' confusion over the diagnosis, half of the parents reported that the assessment helped them to develop more empathy toward their children, which helped them cope more effectively. Mollie, Kerry and Darla all reported that their increased empathy was a result of more awareness that some of the frustrating behaviors their



children were exhibiting may have been the result of a learning problem, and therefore, not necessarily within their control. Silver (1988) believed that this awareness and understanding was particularly important for parents whose children possessed both a learning disability as well as behavioral or emotional difficulties. Many parents in this study expressed the need for ongoing support in order to help them to not only gain a better understanding of the learning needs of their children, but also to help them develop strategies to meet their children's academic, social, and emotional needs. Orlando and Bartel (1989) argued that parents are often in need of support beyond the formal assessment, and suggested that while most of the focus of interventions with children with learning disabilities is based in the classroom, very little is focused on helping parents work with or understand their children.

Information seeking is often seen as a coping strategy (Pain, 1999). Parents in this study reported many examples of information seeking. Pain reported that the quest for information served several functions. First, it contributed to the process of acceptance, not only at the time of acceptance, but later as parents learned more about their children's difficulties. This appeared to be the case for Kerry who reported greater feelings of acceptance and understanding once she read the assessment report and attended a parent workshop. Secondly, Pain stated that information enables parents to manage their children's behaviors and access services and benefits that eased their task or raising a child with a disability. In this study, parents described some instances of improved ability to manage their children's behaviors, but the lack of clear diagnostic information may have impeded parents' ability to use the information to seek these other supports.

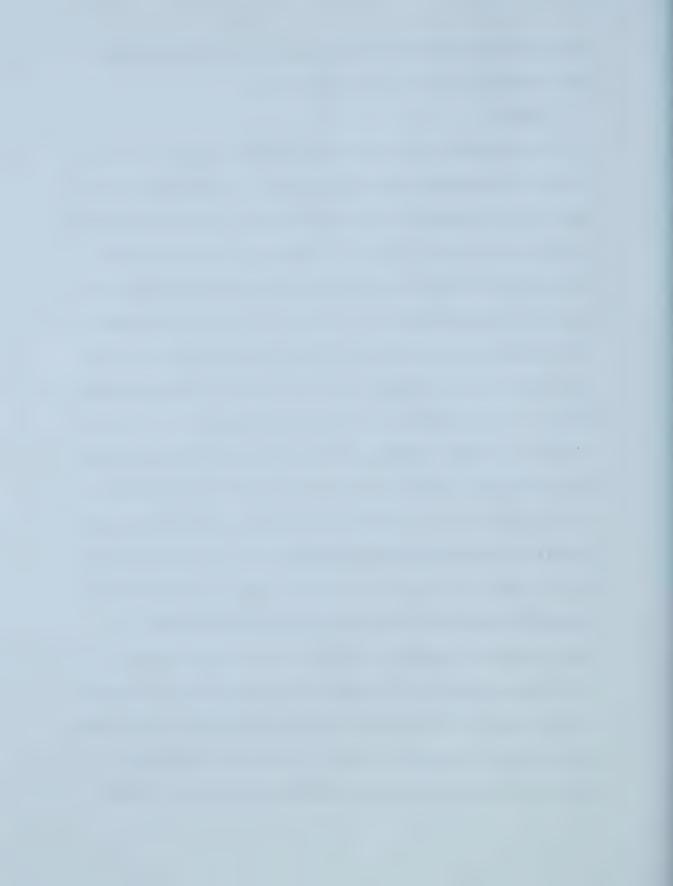


Although parents expressed desire to pursue supports both in and out of school, they indicated continued confusion over which direction to take.

Supports.

A report summarizing the assessment results is a potentially important source of information for parents once the assessment is complete. Turnbull (1983) reported that parents often feel overwhelmed during the feedback session, and as a result, they may not recall the assessment results or discussions. The report can be a source of additional information; however, Cornwall (1990) found that parents had difficulty understanding the report due to their lack of familiarity with the format and terminology. Parents in this study had varying views of the usefulness of the report. Half of the parents stated that they found it a very useful tool that they would utilize on a ongoing basis to ensure their children's needs were met despite their difficulties understanding the technical aspects of the reports (i.e., the scores and testing terminology). They stated that they appreciated the detailed information that was provided. In addition, they indicated that they would focus on ensuring the recommendations were followed through. This tendency was also reported by Cornwall who found that parents often rated the recommendation section of the reports as the most favorable. Parents in this study who did not feel that the report was a useful tool, explained that they felt the report did little to expand their understanding of their child, and had less faith in the recommendations provided.

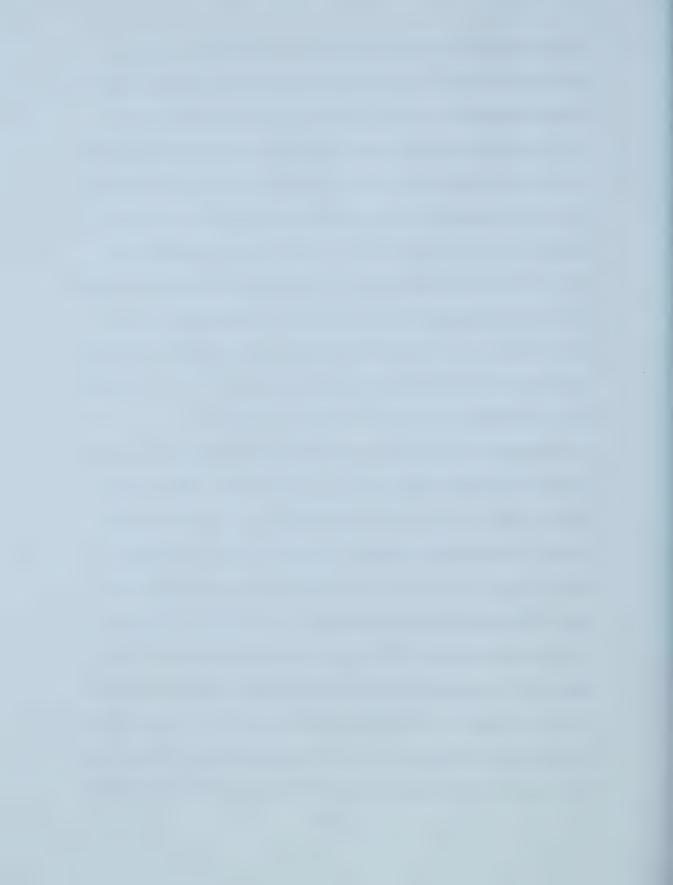
All of the parents in this study indicated that they viewed the school as a resource for their children, and that school personnel were often the individuals they would turn to for additional support of information. In his study of mothers whose children attended special programs for children with learning disabilities, Stephenson (1992) found that



mothers often reported that the teacher was the most frequent and most important communication channel and source of information. Pain (1999), in his study of parents of children with disabilities, found that professionals are the most common source of information for parents, and that personal communication was the most frequently cited form of communication reported. Parents in this study listed doctors, counselors, and other medical personnel (e.g., occupational therapists), as professionals outside the school that they had consulted, or they would consider consulting regarding their children. However, two of the parents in this research who had taken their children to see a play therapist had expressed frustration due to the lack of direction and concrete suggestions they perceived receiving from this professional. As Stephenson found in his research, parents were most interested in professionals who focused on specific problems and stressed changes in behavior rather than developmental insight.

McDonald et al. (1999) suggested that in addition to these formal supports, parents may also access informal supports such as friends, family members and co-workers. Waggoner and Wilgosh (1990) also reported that parents of children with learning disabilities utilized these types of supports. Parents in this study explained that the informal supports they received from the people in their lives provided them with a source of ideas and information as well as a place to vent frustrations and concerns.

Parents in this study reported feelings of loneliness despite access to both formal supports in their communities as well as the informal supports of friends and families. Following the assessment, parents reported continued stress as they felt responsible for ensuring that their children's needs were met both in and out of school. Although most felt that teachers and other school personnel were making efforts to help their children,



parents understood that it was them alone who would ultimately have to monitor their children's progress and continue to advocate on their behalf. This feeling of loneliness was also identified by Waggoner and Wilgosh (1990) in their study into the concerns of parents of children with learning disabilities. They reported that although discussed both informal and formal supports, often their only form of support was "one another" (Waggoner & Wilgosh, p. 98). In this research, mothers reported feeling alone in their quest to find answers and support for their children, and although they often had the support of their spouses, their differing opinions as to the severity of the difficulties was a cause of stress, and at times, intensified their feelings of loneliness.

#### Family adaptation.

Parents involved in this research described peripheral involvement in the assessment of their child who was subsequently diagnosed with a learning disability. Although no standardized measures of family adaptation were administered, this study suggests that the assessment had some impact on family adaptation, and that overall, these families were adapting well. This view of families and how they adapt to the demands of having a child with a disability is supported by a coping perspective (e.g., Kysela et al., 1992; McDonald et al., 1999). In contrast to the pathological perspective where families with children with disabilities are analyzed to reveal the differences between them and families who have no children with disabilities, the coping perspective emphasizes the ways in which families adapt to having a child with a learning disability.

The parents who were interviewed for this research reported that having a child with learning difficulties often adds additional stress, particularly when a child is experiencing social or emotional problems as well. Although parents were coping as best they could,



parents who recognized the struggles their children were having hoped that the assessment would provide them with answers so that they could understand their children's difficulties and find ways to overcome their challenges. Only parents with prior experience with the assessment process felt they understood what had occurred during the assessment, and felt prepared to understand the assessment results. Despite the fact that parents felt a good deal of confusion over the diagnosis made and reasons for their children's difficulties, they reported some enhanced coping skills, added empathy, and ongoing efforts to seek supports to help their children overcome their challenges. Pain (1999) suggested that this seeking of information might be one of the best signs of positive family adaptation to having a child with a learning disability.

A more family-centered approach to assessment might involve parents throughout the assessment process, and intervention strategies would be developed in a manner that promotes positive family functioning. By helping families enhance their understanding of their children's learning needs, reframe or redefine a difficulty in positive terms, as well as appraise their families' areas strengths and needs, professionals could work together with families to enhance existing skills in the family. This approach to assessment and intervention is based on the premise that children's abilities are inextricably intertwined with the strengths, beliefs and needs of their parents and other family members, and that the progress that children make in school will be maximized if professionals work with parents to access the many strengths and resources that they possess.



#### Limitations

This study provides insight into parental experiences of the assessment of children who were diagnosed with a learning disability. Although the information gathered through the interviews and analyzed using a qualitative framework provided a rich source of data, there are several limitations to its generalizability. These limitations include the purposive sampling technique, as well as the interaction between the investigator and the participants. In addition, because assessment practices vary from school district to school district as well as from practitioner to practitioner, results of this study may not generalize to other districts. Also, the retrospective nature of portions of the interview may limit its accuracy. Finally, the variability in the diagnostic criteria used to establish the presence of a learning disability might limit the generalizability of this research.

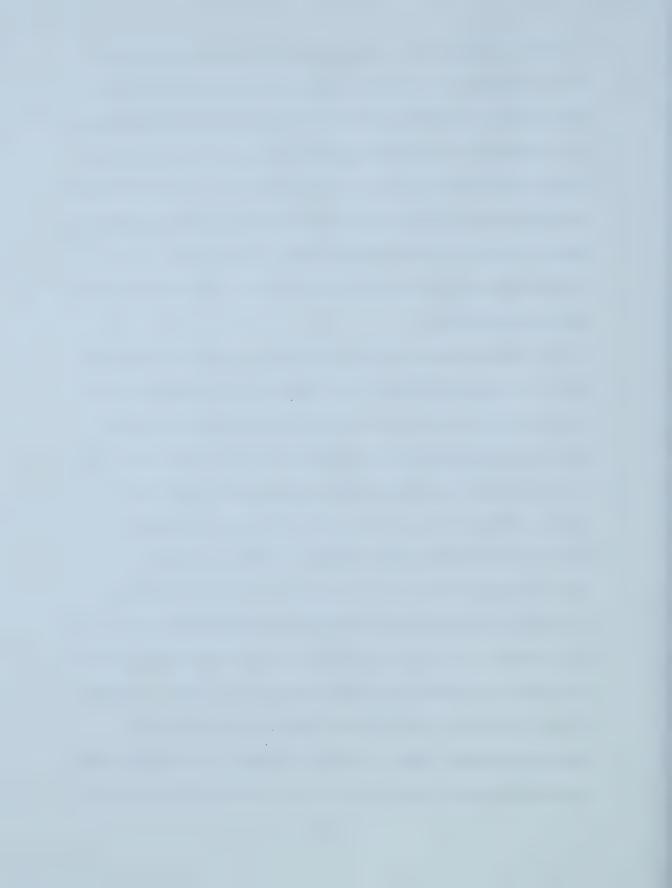
Sampling for this research was not representative which limits its generalizability. The Director of Special Needs for Northville selected parents from her district who met the criteria. Although the characteristics of the parents and their children were quite varied in many aspects (e.g., level of education, number of children, prior experience with learning disabilities), no attempt was made to select a sample that was representative of the population. Another factor that may limit the generalizability of this research was that the children who were diagnosed were homogeneous in that they all scored higher on the Verbal scale of the intellectual assessment than on the Performance scale. These factors limit the generalizability of the findings to populations beyond those described in the sample. However, all parents who were contacted agreed to participate in the research, and therefore there was no concern that the parents who did agree had different perceptions than those who did not.



An additional factor that limits the generalizability of this study is that the school district from which most of the parents were selected may not reflect the practices of other school districts or practitioners. The Northville School District hired consultants to conduct assessments. These consultants visited schools regularly, reviewed cumulative files, gathered information from teachers, conducted assessments, provided feedback, and wrote extensive reports summarizing their results and findings. Although the parent from Edmonton, the larger urban district, reported similar experiences despite somewhat different assessment practices, parental experiences may vary when assessment processes vary from those described.

Data collection methods designed for use in this study contained an interaction effect between the investigator and the participants. Although attempts were made to account for my bias by asking open-ended questions and by actively listening to responses, parents may have been inadvertently influenced by my verbal or nonverbal cues. In fact, this is almost certainly the case as the questions that were asked, my reactions to responses, and further inquiries may have influenced parents. Although attempts were made to remain as neutral as possible, the impact of these biases is unknown.

Part of this research was retrospective in nature which may have lead to some inaccuracies in parents report of events. Parents were asked to recall feelings and events that had occurred, in some cases, years prior to the interviews. For example, parents were asked to recall when they first began to have concerns about their children. They were also asked to recall specific details of the assessment process that, in some cases, occurred 6 months earlier. Although other forms of data gathering were utilized in order to ensure the dependability and trustworthiness of the information, long-term memory is



a variable that may have altered accurate recall of events. It would have been valuable to interview parents before their children were diagnosed with learning disabilities; however, prospective enrollment of parents would be unrealistic as a design study.

A final limitation of the generalizability of this study is that the criteria used to diagnose a child with a learning disability varies significantly from school district to school district, and in some cases from practitioner to practitioner. Although most professionals in the field agree that a learning disability involves a discrepancy between learning potential and achievement, some experts challenge this notion. Stanovich (1999) stated that, "The term learning disability is redundant and semantically confusing... the term LD does nothing but confuse" (p. 350). The children from Northville whose parents were interviewed for this study, were diagnosed based on the criteria outlined in the Definitions section of Chapter 1 of this thesis. The child Edmonton was diagnosed based on more stringent guidelines involving standard scores and percentile ranks. The issue of whether or not these criteria are appropriate is not being addressed in this study. Practitioners who read this study must evaluate the degree to which the research findings can then be generalized to their own situation.

# Implications for Further Research

This study described parental involvement in the assessment of their child with a learning disability, and the effect that their involvement had on their ability to meet the academic, social and emotional needs of their children. The parents in this study described minimal involvement in the assessment process despite the fact that the majority of them had requested it. Although the parents viewed the assessment as a potential for helping them understand their children, they remained confused about the



diagnosis, and felt that they needed more support in order to gain a better understanding and to implement effective coping strategies and supports.

Additional research needs to be conducted with parents from other school districts in order to establish whether the perspectives of these parents generalize to other areas.

Because it is likely that other districts (or other consultants/psychologists) employ different models of assessment, it is possible that parental perspectives may vary. It would also be revealing to conduct quantitative research into the nature and extent of parental involvement in assessments on a larger scale.

Additional research comparing family adaptation of parents who have had greater involvement in the assessment with those families who have had only minimal involvement may provide some useful information that helps to quantify and explain the value of parental involvement.

#### Recommendations

The purpose of this research was to gain insight into how parents perceive the assessment process not to evaluate the services provided by the psychologists and consultants who conducted the assessments. However, several recommendations have surfaced as a result of this research that may apply to many practitioners who conduct assessments, and to school personnel who are involved in the process:

1. <u>Information regarding the purpose and process of assessment should be supplied to parents before the assessment</u>. Parents stated that they had little understanding of what was going to occur during the assessment, and this made it harder for them to prepare their children for what they would be undertaking. It also made it difficult for the parents to prepare for the kind of information they would be receiving as a result of the



assessment. To remedy this, it would be simple (and inexpensive) to provide written information to parents explaining the assessment process, its purpose, and the kinds of information that would result from it. This information could also provide suggestions for parents regarding how they might prepare their children for the assessment. When the feedback session is arranged, additional information could be provided that lists who would be attending the session as well as some of the questions that parents may want to ask.

- 2. Soliciting of parental views and information should occur as part of the assessment. In this study, provisions were not made for direct parental input as part of the assessment process. Ideally, parents could be interviewed prior to the assessment in order to provide relevant developmental, medical, family, and educational history. In addition, parental perspectives of the problem the child is experiencing, coping mechanisms, supports, and appraisals could also be discovered. If there is no funding available for this additional time, parental input could be gained through a questionnaire completed prior to the assessment. This soliciting of parental views from the onset may provide more complete diagnostic information, and would allow practitioners better understanding of the many strengths that families possess. A more family-centered approach would also involve parents in planning interventions.
- 3. <u>Assessment results should be explained using visual representations.</u> Although it is likely that parental experiences of the feedback session would vary with the personnel providing the feedback and attending the session, parents in this study indicated that they were often baffled by the test results that were reported. However, they reported that they found the graph of the WISC-III results to be informative because it provided a



visual representation that they found easier to understand than simply listening to information reported verbally. In addition, they stated that they would have liked to have seen more of what their children had done. It seems prudent to try to incorporate more of the results (e.g., the achievement tests) into a visual format, and to show some of the actual tests or subtests to parents, particularly those on which their children demonstrated significant strengths or weaknesses.

- 4. Opportunities for parental support should be established following the assessment.

  Parents need opportunities for ongoing support beyond the assessment so that they can develop a better understanding of their children and enhance their coping strategies, including homework routines and parenting skills. Having a child with a learning disability can have considerable impact on a family, and parents may require more than a single formal meeting to answer all of their questions and to provide the support that they require. Additional opportunities to meet with professionals or to attend information sessions or support groups may be helpful.
- 5. Better integration of achievement tests results and intellectual, behavioral and emotional assessment results should be emphasized. The assessments completed by the personnel in Northville were in many ways, quite comprehensive. There was often an extensive summary of background information including previous school interventions, teacher observations, and other information gathered from the children's cumulative file, as well the administration of the intellectual assessment, behavioral checklists when appropriate, and in one case, a classroom observation. Recent results of achievement testing were also reported in some of the reports. However, achievement testing was not always reported, or appeared incomplete. For example, tests of written language



appeared to be either not administered, or were not reported. This was particularly disarming when the concerns reported by teachers revolved around a child's struggle with written expression, and yet there was no mention of any written language measures. Limited information regarding achievement test results in reports made it difficult to integrate information regarding the skills the child possessed with the results of the intellectual assessment in order to make a clear and decisive diagnosis. Clear diagnoses were missing from most of the reports, and this added to parents' confusion and stress.

In Edmonton, the reading assessment and the intellectual results were administered and reported separately. A report detailing the reading assessment results was complete, but no report was issued summarizing the intellectual results because the psychologist went on a prolonged sick leave. Only a summary of the scores was made available. In both districts, the separation of achievement testing from intellectual and behavioral assessments did not allow for well-integrated information and specific diagnoses, but promoted the application of general labels.

6. More focus should be placed on specific activities and strategies that parents can implement at home. Because the focus of most interventions was on school-based activities, parents often felt that they did not have enough direction to support their children at home, particularly when it came to homework routines, but also in other academic and social areas. Parents not only wanted to know why their children were struggling, but what specific tasks they could undertake to help them. More specific recommendations during the feedback session and in the report addressed directly to parents based on their concerns may be helpful.



#### Conclusion

When a child is diagnosed with a learning disability it has ramifications for not only the child, but also parents, extended family, and siblings. This ecological view of learning disabilities also suggests that the learning difficulties experienced by a child may be the product of the child's unique pattern of cognitive functioning combined with his or her educational and family environments (Green, 1989). Parental involvement in the psychoeducational assessment of their child ensures that the practitioner has more complete background information that may result in more comprehensive and accurate assessments. In addition, parental involvement helps set the stage for greater acceptance and understanding of the learning disability, which in turn provides parents with more opportunity to utilize their strengths and resources in order to meet the needs of their child. Parental understanding and involvement may reduce stress and enhance family functioning (Morrison & Cosden, 1997). Parental involvement in tutorial and counselling programs has also been demonstrated to improve the academic achievement, emotional well being, and social skills of children with learning disabilities (Cooper & Nye, 1994; Kay, Fitzgerald, & Mellancamp, 1994; Orlando & Bartel, 1989; Stoll Switzer, 1985).

This study was undertaken due to a lack of research into parental experiences of assessment of children with learning disabilities. Although models of parental involvement exist (e.g., Alberta Education, 1996) I was unable to find information regarding the frequency of implementation of such models, nor was I able to find research that addressed the affect the assessment process has on parents' and on families' ability to adapt. A qualitative research design was chosen in order to obtain rich and descriptive data to enhance practitioners' understanding of parental perspectives of the



assessment process. The data that resulted from this research suggests that for the parents involved in this study, positive family adaptation was occurring both before and after the assessment. Although parents described involvement with school personnel prior to the assessment, they described little or no direct involvement in the assessment process, a lack of understanding of what their child was undergoing, and confusion over both test results and diagnoses. Despite this, parents used the information they had to continue to support their children and to seek out more answers.

It is my hope that this study will act as a springboard into further research into parental involvement in assessment, and that it will lead to more family-centered practices where the strengths and capabilities of parents are recognized and utilized.



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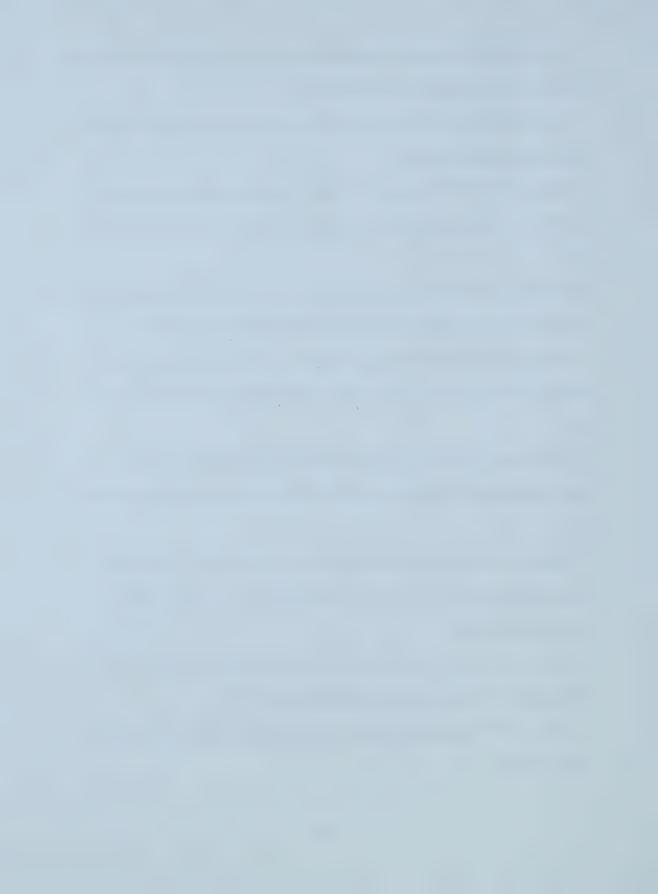
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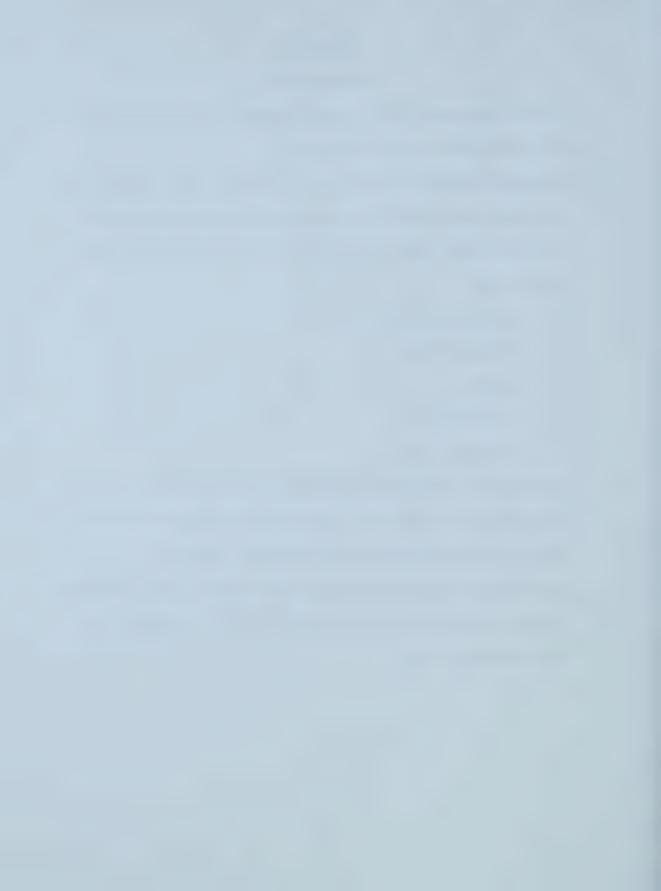


### Appendix A

### Diagnostic Criteria

The following diagnostic criteria are used by Edmonton Public Schools (1999) in order to classify children with learning disabilities:

- Assessment of academic achievement within the current school year on at least four
  of the academic areas listed below on measures which require the student to write,
  calculate, or respond orally, and achievement below the 10th percentile on at least
  two of the areas.
  - -reading comprehension
  - -reading decoding
  - -spelling
  - -written language
  - -mathematics; and,
- Average or above average intellectual ability (IQ 100+) as measured on an individual assessment which includes at least 10 subtests and is not more than 2 years old; and,
- Discrepancies among or between cognitive and academic skills; and,
- Evidence that the academic delay is not due to lack of schooling, sensory or physical handicap, English as a second language, cultural deprivation, or instruction in more than one language (p. 98).



### Appendix B

#### Interview Guide

The following questions are intended as a guide to the semi structured interview of parents. They will be used to help focus the interview and to ensure that a similar breadth of information is covered by all individuals. The questions will only be asked directly when parents do not spontaneously discuss the specific areas while discussing their experiences before, during and after the assessment.

- 1. What were parental concerns, feeling and expectations prior to the assessment?
- How did you first become aware that your child was having learning difficulties?
- How long were you aware of these problems?
- What kind of help was your child receiving in or out of school prior to the assessment?
- Who first suggested that your child should undergo an assessment?
- How were you notified that an assessment would be undertaken?
- What were your feelings when the assessment was arranged?
- What was your understanding of the assessment process?
- 2. What are parental perceptions of their role in the assessment?
- In what ways were you involved in the assessment process?
- What contact did you have with the school psychologist?
- What kind of information was obtained from you?
- 3. What are parental experiences of the feedback session?
- What happened during the feedback session?
- Who attended the session?



- Who spoke during the session?
- What conclusions were made?
- What did you learn about your child?
- How did you feel during that session?
- What do you think your role was in the session?
- 4. How does the assessment and subsequent diagnosis affect family adaptation?
  Specifically, how does the assessment and diagnosis enhance parental understanding of their child's learning disability, promote the development of support systems, and enhance coping strategies?
- How would you define or explain what a learning disability is?
- What is your understanding of the nature of your child's learning disability?
- What kind of effects does having a child with a learning disability have on your family?
- What kind of assistance will your child be receiving now that a diagnosis has been made?
- Who has helped you the most to deal with your concerns?
- Has anything changed in your family since your child was diagnosed? (For example homework routines, expectations)?
- What community resources are you aware of that you may be able to use to help your child?
- Who can you call or ask when you are not sure how to help your child?
- Are there any aspects of your child's learning needs that you feel you need to learn more about?



How do you think having a child with a learning disability has affected you.		
	145	



# Appendix C

## Research Consent Form

Ι,	, hereby consent to be			
•	Interviewed			
•	Tape recorded			
Ву	Michele Pentyliuk			
Ιu	inderstand that:			
•	I may withdraw from the research at any time without penalty			
•	All information gathered will be treated confidentially and discussed only with your			
	supervisor			
•	Any information that identifies me will be destroyed upon completion of this research			
•	I will not be identified in any documents resulting from this research			
I also understand that the results of this research will be used only in the following:				
•	Research thesis			
•	Presentations and written articles for other educators			
Sig	gnatureDate			
W	itnessDate			
Fo	r further information concerning the completion of this form, please contact Michele			
Pe	ntyliuk at 436-4704 (residence) or 439-5683 (business), or Dr. Fern Snart at 492-2218.			
I a Sig	<ul> <li>supervisor</li> <li>Any information that identifies me will be destroyed upon completion of this research</li> <li>I will not be identified in any documents resulting from this research</li> <li>I also understand that the results of this research will be used only in the following:</li> <li>Research thesis</li> <li>Presentations and written articles for other educators</li> </ul>			



# Appendix D

# Consent for Release of Confidential Information

I,		, hereby authorize
		to release the
psychoeducational assessment	report(s) concerning	
		to Michele
Pentyliuk. I hereby waive any	and all claims against	
	for any purposes	whatsoever in connection with
the communication and disclose	ure of the above informatio	n.
Signed at	, this	day of,
2001.		
Signature:		
Witness		



# Appendix E

# Field Note Summary

Content (e.g., topics, focus, exact words, what stands out)	Code Name
Non-Verbal  (e.g., tone of voice, facial expressions, body posture, tone of interview, hand gestures, eye movements)	Date of Interview
Investigator's Impressions (e.g., emotional responses, discomfort with certain topics, sense of person, personal thoughts)	Starting Time
Analytical Processes (e.g., questions, hypothesis, inferences, patterns or themes, interpretations)	Ending Time



#### Appendix F

#### Participant Information Letter

Study Title: Parents' Experiences of the Psychoeducational Assessment of Their Child

with a Learning Disability

Researcher: Michele Pentyliuk

Phone: 436-4704 (residence)

439-5683 (office)

492-5245 (Ed. Psy. General Office)

Dear Study Participant,

The purpose of this study is to learn about the experiences, concerns and feelings of parents whose children have been assessed with a learning disability. As part of this study, you are being asked to participate in two to three one-hour interviews. The first interview will focus on your personal experiences surrounding the assessment of your child. The second interview will provide you with the opportunity to expand this information as you reflect on your earlier interview. A third interview, if necessary, will be conducted to clarify any final questions. During the interview, I may ask for clarification of a particular point, but will mainly listen to you share your perceptions with me. Each conversation will be audio-taped and transcribed by me or by a typist who will maintain confidentiality. The interview will take place in a location that is most convenient for you. The information gathered through this study is intended to help those professionals who conduct assessment gain insight into parents' perspectives, experiences and concerns surrounding the assessment process.



In addition to the interview, I will ask for your permission to obtain a copy of the assessment report completed by the school psychologist. This will help me understand the nature of your child's learning difficulty. If you do not have a copy of the report, with your written consent, I can obtain a copy from the psychologist.

This study will be conducted as a Master's Thesis under the supervision of Dr. Fern Snart, Associate Dean of the Faculty of Education, and Dr. Linda McDonald, Professor in the Department of Educational Psychology, University of Alberta. All information is confidential and the identity of participants, as well as the name of any other person mentioned, will not be identified with the data. The audio-tapes will be stored in a locked space during the study, and erased following the completion of the study. You will be free to withdraw from the study at any time, and for any reason.

Please contact me if you require any additional information.

Sincerely,

Michele Pentyliuk

Master's Student

Department of Educational Psychology

University of Alberta



#### Appendix G

## Oath of Confidentiality

Study Title: Parents' Experiences of the Psychoeducational Assessment of Their Child

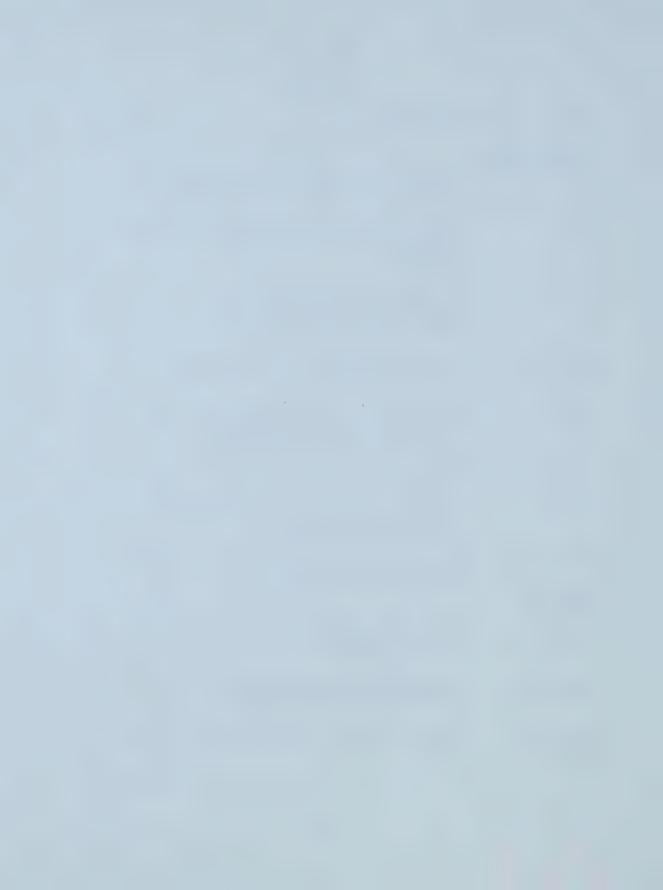
with a Learning Disability
Researcher: Michele Pentyliuk
Department of Educational Psychology
University of Alberta
All persons associated with the research project are asked to sign an Oath of
Confidentiality.
I,, swear (or solemnly affirm) that I will diligently,
faithfully and to the best of my ability, execute according to the law, the duties required
of me as typist. I will not, without undue authorization, disclose or make known any
matter or thing that comes to my knowledge by reasons of my involvement in the service
of this project.
Taken and subscribed before me at
This, 2001
Witness



# Appendix H

## List of Codes

Name	Operational Definition	Code
Pre-Assessment Support	Personal, social or academic supports that are in place prior to the assessment being completed	PS
Demands	Stressors, difficulties or a challenges facing the family as a result of the child's learning difficulties	PD
Feelings	Emotions and feelings regarding the assessment, or prior to the assessment as a result of the learning difficulties	PF
Parental Involvement	The nature and amount of parental involvement prior to the assessment	PPI
Appraisals	Parents knowledge of the nature of the child's learning difficulties, the term learning disability, and the nature or the assessment	PA
Initiation	Who was it that initiated the assessment?	PI
Coping	Strategies parents implement to help them copetheir problem-solving strategies	PC
Family Functioning	How the family appears to be functioning overall prior to the assessment	PFF
During the Assessment Parental Involvement	Nature and amount of parental involvement during the assessment	DPI
Background Information-Cum.	Background information gathered by the psychologist from the cumulative file.	DBI-C
Background Information- Teacher	Background information gathered from the teacher	DBI-T



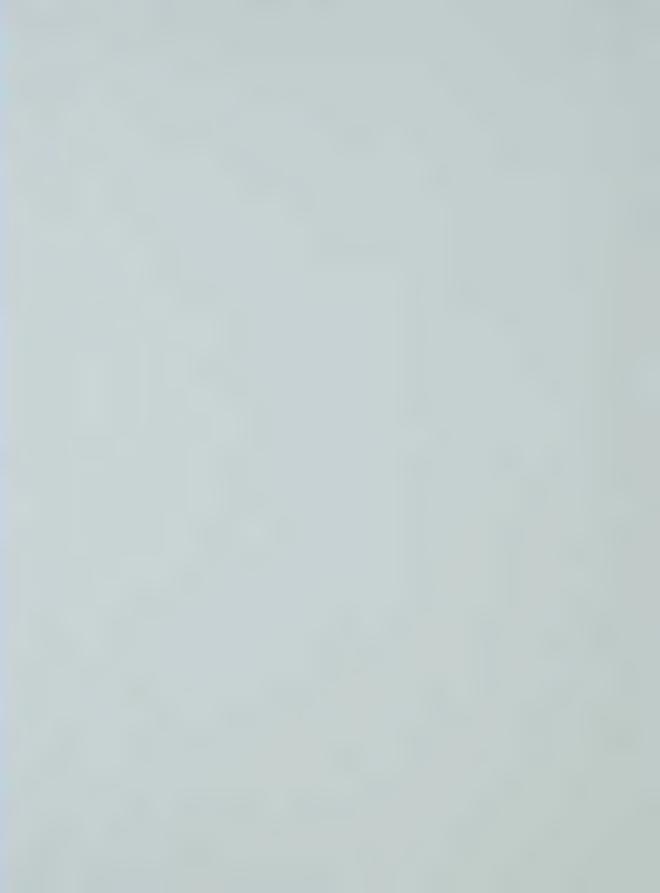
Background Information- achievement testing	Background information gathered from some source, but specifically regarding recent achievement testing	DBI-A
Background information-parents	Background information gathered directly by the psychologist from parents at the time of the assessment	DPI-P
Background information-student	Background information gathered by the psychologist directly from the child being assessed	DPI-S
Feedback session Participation	Names of individuals who participated in the feedback session as well as the ways in which they participated	FP
Information	The kinds of information that was presented at the session including description of tests, scores, results, conclusions etc.	FI
Appraisals	Ways in which the information helped parents understand their child's learning disability/ learning needs.	FA
Supports	The types of supports that were discussed in the feedback session, including school, community or home based.	FS
Roles	The role the parent(s) felt that they played during the feedback session.	FR
Integration of info.	The way in which information from the assessment was integrated with the information about child's functioning in and out of school.	FII
Feelings	Feelings that parents experienced during the session.	FF



After the Assessment		
Supports	Supports that the family have utilized or know are available in the community, school or home.	AS
Coping	Strategies that the family is now utilizing or is planning to utilized following the assessment	AC
Appraisals	Current views of the parents concerning their child, and their family. What do they see in the future for their child, how do they view learning disabilities	AA
Family Functioning	How the family appears to be functioning overall following the assessment.	AFF
Feelings	Feelings expressed by the family now the assessment is complete.	AF
Demands	The pile-up stressors and demands faced by the family now that the assessment is complete.	AD
Definition of LD	Parents' understanding of LD- what does the term mean?	ALD















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